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ABSTRACT

Ten topic papers examine federal laws and programs affecting persons with disabilities and make recommendations for improved use of federal money. The papers cover: (1) equal opportunity laws, examining the status of disability-related equal opportunity laws and identifying gaps in coverage, shortcomings and inconsistencies in interpretation and application, and deficiencies in enforcement; (2) employment, focusing on transition programs, supported work, placement initiatives, and sheltered employment; (3) disincentives to work under social security laws; (4) prevention of disabilities, addressing existing programs, problems, and gaps in legislation and programs; (5) transportation, focusing on urban mass transit, air travel, bus travel, Amtrak, and private transportation; (6) housing, dealing with federal housing assistance and loan programs as well as nondiscrimination and fair housing requirements; (7) community-based services for independent living, which explores services for individuals with various levels of handicap and the costs and benefits of community-based independent living services; (8) educating children with disabilities, dealing with early childhood and preschool programs and integration of special education classes and programs into regular educational settings; (9) personal assistance, which outlines issues and national policy for providing attendant services; and (10) coordination of policy development and of program administration. (JDD)

INDEPENDENCE

An Assessment of Federal Laws and Programs Affecting Persons With Disabilities — With Legislative Recommendations

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EC 211757

A REPORT TO THE PRESIDENT AND THE CONGRESS OF THE UNITED STATES

APPENDIX: TOPIC PAPERS

TOWARD INDEPENDENCE:

AN ASSESSMENT OF FEDERAL LAWS AND PROGRAMS AFFECTING PERSONS WITH DISABILITIES-- WITH LEGISLATIVE RECOMMENDATIONS

February, 1986

National Council on the Handicapped

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APPENDIX

to

TOWARD INDEPENDENCE: AN ASSESSMENT OF FEDERAL LAWS AND PROGRAMS AFFECTING PERSONS WITH DISABILITIES-- WITH LEGISLATIVE RECOMMENDATIONS

Publication Date: February 1, 1986

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The Council wishes to acknowledge and convey its sincere appreciation to the many individuals and organizations who contributed to these topic papers. Numerous people with disabilities, parents, service providers, advocates, business persons, legislative policy advisors, and other experts from all the fifty States contributed to this effort by participating in public forums, attending advisory meetings, and otherwise providing input and assistance to the Council in the process of developing the ideas and recommendations contained in the appendix.

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DESCRIPTION OF THE NATIONAL COUNCIL ON THE HANDICAPPED

The National Council on the Handicapped is an independent Federal agency comprised of 15 members appointed by the President of the United States and confirmed by the Senate. Established by the 95th Congress in Title IV of the Rehabilitation Act of 1973 (as amended by Public Law No. 95-602 in 1978), the Council was initially an advisory board within the Department of Education. In 1984, however, the Council was transformed into an independent agency by the Rehabilitation Act Amendments of 1984 (Public Law No. 98-221).

The Council is charged with reviewing all laws, programs, and policies of the Federal Government affecting disabled individuals and making such recommendations as it deems necessary to the President, the Congress, the Secretary of the Department of Education, the Commissioner of the Rehabilitation Services Administration, and the Director of the National Institute of Handicapped Research (NIHR). The Council is given explicit authority to establish general policies for and monitor the performance of NIHR, and to review and approve standards concerning Independent Living and Projects With Industry programs. In addition, the Council has been statutorily directed to submit to the President and the Congress, by February of 1986, the present report analyzing Federal programs and presenting legislative recommendations to enhance the productivity and quality of life of Americans with disabilities.

Whereas many government agencies deal with issues and programs affecting people with disabilities, the National Council on the Handicapped is the only Federal agency with the mandated responsibility to address, analyze, and make recommendations on issues of public policy which affect people with disabilities regardless of age, disability type, perceived employment potential, perceived economic need, specific functional ability, status as a veteran, or other individual circumstances. The Council recognizes its unique opportunity to facilitate independent living, community integration, and employment opportunities for people with disabilities by assuring a coordinated approach to addressing the concerns of persons with disabilities and eliminating barriers to their active participation in community and family life.

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INTRODUCTION

The National Council on the Handicapped is charged by statute with reviewing Federal laws and programs affecting persons with disabilities and assessing the extent to which they "provide incentives or disincentives to the establishment of community-based services for handicapped individuals, promote the full integration of such individuals in the community, in schools, and in the workplace, and contribute to the independence and dignity of such individuals."

Our nation's current annual Federal expenditure on disability benefits and programs exceeds $60 billion. This report proposes some fiscally responsible approaches for spending disability-related dollars more prudently and productively. The Council is strongly convinced that present and future costs of disability to the nation are directly related to the degree of success we attain in reducing existing barriers, both structural and attitudinal, and in providing appropriate services to individuals with disabilities so that they may realize their full potential and become more independent and self-sufficient.

The Council has focused in detail upon ten major topic areas of particular importance to individuals with disabilities. These topics are discussed extensively in the individual topic papers presented in this Appendix. The Council's legislative recommendations in regard to the ten issue areas are summarized in the body of the report. They include the following:

> Equal Opportunity Laws: The Council recommends that enactment of a comprehensive law requiring equal opportunity for individuals with disabilities, with broad coverage and setting clear, consistent, and enforceable standards prohibiting discrimination on the basis of handicap.

Employment: To increase employment among people with disabilities--a drastically underemployed segement of the population--the Council recommends several legislative changes, concerning the transition from school to work, supported employment, private sector initiatives, job training, job development, and placement.

Disincentives to Work Under Social Security Laws: The Council outlines several ways in which provisions of existing Social Security laws--Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), Medicaid, and Medicare--serve to discourage and penalize people with disabilities if they seek to become employed and self-supporting. In response to these work disincentives, the Council recommends corrective amendments to the problematic provisions.

Prevention of Disabilities: To promote the prevention of disabilities and to assure that individuals having disabilities do not suffer unnecessary secondary disabilities or exacerbation of their impairments, the Council recommends that the Federal Government mount a national program for the prevention of disabilities.

Transportation: The Council recommends amendments to Federal transportation legislation to achieve the nation's established policy that "disabled people have the same right to use public transportation as nondisabled persons." Proposals relate to urban mass transit, air transportation, and private vehicles.

Housing: To permit people with disabilities an opportunity to obtain appropriate housing, which is an important prerequisite to obtaining employment, living independently, and avoiding costly institutionalization, the Council makes several recommendations designed to prohibit housing discrimination and to promote increased appropriate and accessible housing for persons with disabilities.

Community-Based Services for Independent Living: To achieve productivity and independence, people with disabilities require a range of support services according to the nature and degree of their disabilities. The Council proposes a variety of measures, including amendments and funding support under Parts A and B of Title VII of the Rehabilitation Act, to promote the availability of community-based services for independent living.

Educating Children with Disabilities: The Council makes legislative recommendations regarding educational opportunities for children with disabilities. These recommendations respond to: the need for special education and related services during infancy; the need to educate children with special needs in regular education facilities; and the need to assess progress made since the enactment of the Education for All Handicapped Children Act.

Personal Assistance: Attendant Services, Readers, and Interpreters: Because of the critical importance of such services in fostering independence and avoiding expensive institutionalization, the Council recommends a national commitment to developing a quality system of attendant services, readers, and interpreters.

Coordination: The Council recommends that all Federal and federally supported disability-related programs be authorized and required to develop a joint plan for the systematic coordination of services and benefits.

TOPIC PAPER A:

EQUAL OPPORTUNITY LAWS

National Council on the Handicapped

February, 1986

ACKNOWLEDGMENT

This is one of a series of ten topic papers developed by the National Council on the Handicapped as part of its Special Report to the President and Congress: TOWARD INDEPENDENCE: An Assessment of Federal Laws and Programs Affecting Persons with Disabilities--With Legislative Recommendations. The members of the National Council on the Handicapped wish to expressly acknowledge with appreciation the special contribution made to this paper by Robert L. Burgdorf Jr.

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I. INTRODUCTION

The right to freely and fairly pursue personal, social, and economic opportunities is paramount in any free society. Equal opportunity is a cornerstone of the legal, political, and economic systems of the United States -- the Land of Opportunity. Unfortunately, Americans with disabilities have often not been allowed access to the opportunities for which our society is justly famous.

Disability -- like birth, death, illness, accident, pain, happiness, and sadness -- is a normal part of human life. A majority of individuals who survive to adulthood will experience some form of significant temporary or permanent disability during their lifetimes. That a certain number of people will have disabilities is just as predictable and normal as that there will be tall people, short people, people with fair skin, black people, young people, and elderly people. Yet, because of their disabilities, millions of Americans find themselves denied opportunities that others take for granted and excluded unnecessarily from the productive mainstream of society.

President Reagan has recognized the importance of access to opportunities for persons with disabilities: "For only through opportunities to use the full range of their potential will our disabled citizens attain the independence and dignity that are their due." (President Reagan, 1983, p.124). In heralding the necessity of opening up opportunities for persons with disabilities, President Reagan echoes the statements of previous Presidents and numerous Congressional pronouncements.

The United States Supreme Court has acknowledged "the Federal interest in developing the opportunities for all individuals with handicaps to live full and independent lives" (Community Television of Southern California v. Gottfried, 459 U.S. 498, 508 (1983)).

Providing access to opportunities has generally been chosen over "taking care of" persons with disabilities as the preferred approach of the Federal and many state governments, along with international bodies and organizations of persons with disabilities, for at least the last two decades. Twenty years ago, an article written by a blind law professor and his colleague contrasted the "custodial" and "integrative" approaches to disability:

> The older custodial attitude is typically expressed in policies of segregation and shelter, of special treatment and separate institutions. The newer integrative approach focuses attention upon the needs of the disabled as those of normal and ordinary people caught at a physical and social disadvantage. The effect of custodialism is to magnify physical differences into qualitative distinctions; the effect of integrationism is to maximize similarity, normality, and equality as between the disabled and the able-bodied.
> (ten Broek and Matson, p. 816).

In their laws and official pronouncements, government bodies at all levels of modern American society have, with relative consistency, chosen equal opportunity, full participation, and integration as the desired objectives for people with disabilities (U.S. Commission on Civil Rights, 1983, pp. 67-69). Congress has declared:

> the benefits and fundamental rights of this society are often denied those individuals with mental and physical handicaps;
> ***
> it is of critical importance to this Nation that equality of

> opportunity, equal access to all aspects of society, and equal rights guaranteed by the Constitution of the United States be provided to all individuals with handicaps;
> ***
> it is essential ... that the complete integration of all individuals with handicaps into normal community living, working, and service patterns be held as the final objective
> ***
> (29 U.S.C. section 701 Note, (1976)).

A major obstacle to achieving the societal goals of equal opportunity and full participation of individuals with disabilities is the problem of discrimination. Discrimination consists of the unnecessary and unfair deprivation of an opportunity because of some characteristic of a person. It is the antithesis of equal opportunity.

The severity and pervasiveness of discrimination against people with disabilities is well-documented. The U.S. Commission on Civil Rights' major study of handicap discrimination concluded: "Historically, society has tended to isolate and segregate handicapped people. Despite some improvement, particularly during the last two decades, discrimination against handicapped persons continues to be a serious and pervasive social problem. It persists in such critical areas as education, employment, institutionalization, medical treatment, involuntary sterilization, architectural barriers, and transportation." (U.S. Commission on Civil Rights, 1983, p. 159). Numerous commentators and court cases have documented various examples of discrimination against individuals because of their disabilities. A 1985 decision of the United States Supreme Court recognizes that serious discrimination against persons with disabilities results not only from intentional denials of opportunity, but also from thoughtlessness, indifference, and benign neglect

(Alexander v. Choate, 105 S.Ct. 712, 718 (1985)).

To address the problem of denials of opportunity to persons with disabilities, Congress has enacted several laws prohibiting discrimination on the basis of handicap. Equal opportunity laws for persons with disabilities have been a bipartisan priority. Former President Carter had declared that "antidiscrimination laws are the cornerstone of civil rights for the handicapped" (President Carter, 1980, p. 809). President Reagan has written:

> Our Nation's commitment to equal protection of the laws will have little meaning if we deny such protection to those who have not been blessed with the same physical or mental gifts we too often take for granted. I support Federal laws prohibiting discrimination against the handicapped, and remain determined that such laws be vigorously enforced. (President Reagan, 1982).

In its National Policy For Persons With Disabilities, endorsed by the President, the National Council on the Handicapped called for "a comprehensive, internally unified body of disability-related law which guarantees and enforces equal rights and provides opportunities for individuals with disabilities." Congress has enacted several laws prohibiting discrimination or requiring equal opportunity for persons with disabilities. One of the best-known of such laws is Section 504 of the Rehabilitation Act of 1973, as amended (29 U.S.C. Section 794), which prohibits discrimination on the basis of handicap in programs and activities conducted by the Federal government or conducted by recipients of Federal financial assistance. Section 503 of the Rehabilitation Act (29 U.S.C. Section 793) requires Federal government contractors to take "affirmative action" to employ and advance workers with disabilities. Section 501 (29

U.S.C. Section 791) places a similar "affirmative action" requirement upon Federal government employment. Several other Federal laws prohibit discrimination on the basis of handicap in certain other contexts.

This report examines the current status of disability-related equal opportunity laws and identifies gaps in coverage, shortcomings and inconsistencies in interpretation and application, and deficiencies in enforcement. To address such problems, the Council makes recommendations for the enactment of comprehensive and effective equal opportunity laws for people with disabilities.

II. PROBLEMS WITH THE SCOPE OF COVERAGE

A major problem with current equal opportunity laws regarding disabilities is that the scope of their coverage and enforceability is quite limited.

A. Not Enforceable In Federal Courts Against States

A recent decision of the United States Supreme Court has blunted much of the effect and enforceability of Section 504 of the Rehabilitation Act. In Atascadero State Hospital v. Scanlon (105 S.Ct. 3142 (1985)), the Court ruled that the Eleventh Amendment prohibits suits for monetary damages in Federal court against States and state agencies under Section 504. While the dissenting Justices argued that Section 504's legislative history demonstrated that Congress clearly intended the States to be "among the primary targets of section 504" (Id. at p. 3151), the majority of the Court held that Congress can abrogate the States' immunity from Federal court suits "only by making its intention unmistakably clear in the language of the statute" (Id. at p. 3147). Because Section 504 does not contain such an unequivocal statement that the States may be sued in Federal court, the Court ruled that state agencies are immune from suits for monetary damages under Section 504. Considering the large proportion of Federal financial assistance to States and state agencies, such as state education agencies, state universities, and state residential programs for people with disabilities, the impact of the Court's decision upon the enforceability of Section 504 is considerable. Congressional intent appears to have been thwarted by this ruling, for it is hard to dispute the conclusion of the dissenting Justices that "Congress intended to impose a legal obligation on the States not to discriminate against the handicapped" (Id. at p. 3153).

Consistent with Congressional authority under the Fourteenth Amendment, the statutory prohibition of discrimination on the basis of handicap should extend to all "State actions." This would apply to all officially sanctioned conduct of the States, state agencies, state officials, and county and local governments, acting "under color of state law." The application to local government bodies, including such entities as zoning boards, is consistent with the decision of the U.S. Supreme Court in City of Cleburne, Texas v. Cleburne Living Center (105 S.Ct. 3249 (1985)), which held that a local zoning board's denial of a special exception to permit a group home for mentally retarded people in a residential neighborhood was irrational and violated the Fourteenth Amendment. (For additional discussion of the zoning issue and of the need for a statutory provision addressing it, see the Council's report on Housing).

B. Not Co-Extensive With Laws Prohibiting Discrimination in Employment on the Basis of Race, Color, Religion, Sex, or National Origin

Title VII of the Civil Rights Act of 1964 (42 U.S.C. Section 2000e *et seq.*) prohibits employment discrimination on the basis of race, color, religion, sex, or national origin. It applies to all employers engaged in an industry affecting commerce who have fifteen or more employees, to employment agencies, and to labor unions.

Laws addressing handicap discrimination do not have comparable coverage of employment. They cover primarily employment by Federal government agencies, Federal contractors, and recipients of Federal grants. The fact that a business engages in interstate commerce, which makes it subject to Congressional authority under the U.S. Constitution, does not, under current statutes, give rise to any duty to refrain from discriminating against people with disabilities. There do not appear any sound policy reasons why employers who are prohibited from other types of discrimination should be allowed to discriminate on the basis of handicap.

C. The Program or Activity Limitation

In the case of Grove City College v. Bell (104 S.Ct. 1211 (1984)), the U.S. Supreme Court ruled that an educational institution is covered by the nondiscrimination provisions of Title IX of the Education Amendments of 1972 (20 U.S.C. Section 1681(a)) if some of its students receive Federal grants to pay for their tuition. But the Court ruled that the receipt of such Federal grants does not trigger institutionwide coverage. Since this form of financial assistance, said the Court, represents financial assistance to the college's financial aid program, it is only that program which is regulated by Title IX. Because the pertinent provisions of Title IX are very similar to the language of Section 504, the holding in Grove City has implications for the interpretation and application of Section 504.

The same day that it decided the Grove City case, the

Supreme Court also announced its decision in Consolidated Rail Corporation v. Darrone (104 S.Ct. 1248 (1984)) -- a Section 504 case. The Court mentioned its discussions of the meaning of "program or activity" in the Grove City and North Haven Board of Education v. Bell (456 U.S. 512 (1983)) decisions under Title IX, and stated that: "Clearly, this language limits the ban on discrimination to the specific program that receives federal funds" (104 S.Ct. at p. 1255). The Court did not, however, attempt to define the term "program" in Darrone, but held that that task should be left to the district court. Given the procedural posture of the case, the high Court declined to decide whether Federal financial assistance was received by the "program or activity" that allegedly discriminated against the plaintiff in Darrone.

In response to the Grove City decision and its implications for Title IX, Section 504, and other similar statutes, legislation was introduced during the 98th Congress, but no such bill was enacted. Similar bills, referred to as the Civil Rights Restoration Act, have been introduced in the 99th Congress. Such bills are based upon a conviction that any person or agency that wishes to obtain Federal grant funds should be required to avoid or cease discriminating in all of its activities. Conversely stated, the Federal government should not provide financial assistance to any person or agency that engages in discrimination in any part of its operations or activities.

D. Not Co-Extensive With Federal Fair Housing Act

Title VIII of the Civil Rights Act of 1968 (42 U.S.C. sections 3601 - 3619) prohibits discrimination in housing on the basis of race, color, religion, sex, and national origin. The coverage of Title VIII is extremely broad, applying to almost all types of housing with the exception of certain private, single family dwellings, and facilities owned or operated by religious groups and private clubs.

Section 504 of the Rehabilitation Act of 1973 prohibits discrimination on the basis of handicap only in housing programs or activities of the Federal government or that receive Federal financial assistance. Compared to the coverage of Title VIII, the housing subject to Section 504 is quite limited. Various bills have been proposed that would provide equivalent coverage of handicap discrimination as that provided under Title VIII, generally by simply adding "handicap" to the types of discrimination prohibited in Title VIII. A key element that should be addressed in such proposals is a standard regarding the duty upon landlords, developers, and sellers to make reasonable accommodations for tenants and purchasers with disabilities.

E. Not Co-Extensive With Prohibitions of Other Types of Discrimination in Public Accommodations

Title II of the Civil Rights Act of 1964 (42 U.S.C. Section 2000a) prohibits discrimination on the basis of race, color, religion, or national origin in public accommodations. It applies to a broad range of "places of public accommodation," including inns, hotels, motels, restaurants, cafeterias, lunchrooms, lunch counters, soda fountains, gas stations, motion picture houses, theaters, concert halls, sports arenas, and stadiums, if such facilities "affect commerce" or if the discrimination or segregation is "supported by State action."

There is no comparable provision prohibiting discrimination on the basis of handicap in public accommodations. Except for the relatively rare case in which a place of public accommodation is the recipient of Federal grant funds, no Federal law addresses unnecessary barriers and other forms of discrimination that deprive persons with disabilities of the use of public accommodations. Thus, many hotels, motels, restaurants, theaters, stadiums, and other public accommodations that are prohibited from discriminating against racial, ethnic, and religious groups may with impunity refuse to serve and deny access to their facilities to people because they have disabilities.

F. Failure of the Federal Government to Use Its Leverage as a Consumer of Goods and Sevices

Federal agencies spend large sums of money on contracts and purchases of consumer goods and services. Government agencies rent large numbers of conference and meeting rooms, and pay for many hotel rooms of meeting attendees and government employees on travel. The government purchases a great quantity of airline and train tickets, frequently through arrangements with "contract" carriers. Government agencies also pay for great numbers of rental cars used by government employees, often through agency contracts with particular companies.

Many of the companies from whom the government rents or purchases facilities, goods, and services have not made substantial efforts to make their products and services equally open and usable by government employees and other consumers who have disabilities. Many conference and meeting facilities rented by government agencies are architecturally inaccessible or do not have adequate toilet facilities for persons with disabilities. The government pays the costs for many hotel and motel rooms in establishments that are not accessible and have made no efforts to plan for and accommodate disabled guests. Some of the airlines and train companies that benefit from government travelers have poor records of accommodating individuals with disabilities; many have inaccessible stations and vehicles, and archaic rules and practices that exclude or demean travelers who have disabilities. Rental car companies that reap the benefits of government business often do not provide vehicles with hand controls or other modifications needed by individuals with disabilities, or provide modified vehicles only in certain cities, or upon very different terms from that offered to other people, e.g., at higher rates or requiring that a modified vehicle can be returned only at the original place of rental.

Some organizations of persons with disabilities have made use of their "consumer clout" to get providers of services and goods to be more accommodating to those with disabilities. In selecting a site for national conferences or conventions, for example, some organizations bargain with the management of hotels to make more rooms, restrooms, and other facilities accessible. The Federal government, in contrast, has made no use of its considerable leverage as a consumer of goods and services to improve the lot of government employees and other individuals having disabilities. Rooms are paid for, tickets purchased, and cars leased without any attempt to get the businesses involved to make their facilities and services more open and usable by people with disabilities. The Federal government is squandering an important opportunity to provide leadership and incentive to make the oft-recited goals of equal opportunities, integration, and full participation of disabled people more of a reality in this country. Federal agencies need to send a clear message to hotels, motels, airlines, train companies, rental car companies, and other purveyors of consumer goods and services that they will not do business with those who refuse to provide equal opportunities for customers with disabilities.

G. Other Gaps in Coverage

There are certain other areas in which serious problems of discrimination against people with disabilities are within the scope of Congressional authority to address, but no legislative remedies have been provided under current laws. In the case of Community Television of So. Cal. v. Gottfried (459 U.S. 498 (1983)), the U.S. Supreme Court ruled that, because Section 504 of the Rehabilitation Act of 1973 is silent on the matter, the Federal Communications Commission is not required to ensure that its public television licensees do not discriminate on the basis of handicap. The application of the nondiscrimination requirement to Federal licensees is an issue that should be addressed by equal opportunity laws for people with disabilities, but, to date, has not been.

Interstate travel is another are in which the problems of discrimination faced by persons with disabilities should be explicitly covered by equal opportunity laws. (For further discussion of such problems and recommended approaches for addressing them, see the Council's report on Transportation). Likewise, individuals with disabilities have encountered discrimination in the availability of insurance; frequently individuals are denied certain types of insurance coverage because of presumptions about their increased risks and deficits, even though there may be no adequate actuarial data supporting such presumptions (Baker and Karol, 1978). Problems of discrimination in eligibility for insurance should be addressed in equal opportunity laws for people with disabilities.

III. PROBLEMS WITH THE LANGUAGE, INTERPRETATION, AND ENFORCEMENT OF CURRENT HANDICAP EQUAL OPPORTUNITY LAWS

The nation has had a dozen years of experience under the nondiscrimination provisions of the Rehabilitation Act of 1973. A number of problems with the wording and enforcement of current laws guaranteeing equal opportunities for people with disabilities have come to light.

A. Absence of Reasonable Accommodation Requirement and Standards

A key element of eliminating discrimination on the basis of handicap is the process of matching the particular abilities and limitations of each disabled individual with the essential requirements of a particular activity and trying to modify the activity as necessary to permit the individual with a disability to participate. Legally, this matching and modification process has been imposed as the concept of reasonable accommodation. Reasonable accommodation occurs whenever a service provider or employer provides or modifies devices, services, or facilities, or changes practices or procedures in order to match a particular person with a particular program or activity.

The duty to make reasonable accommodations to the limitations of persons with physical and mental disabilities was first applied in 1976, when the Department of Labor issued regulations affecting government contractors under Section 503 of the Rehabilitation Act of 1973. Over ten years of experience with the reasonable accommodation requirement suggests that it is a workable and effective concept. Concerns about the costs and disruptiveness of the duty to make reasonable accommodations have been found to be largely misplaced. Studies have found that workplace accommodations for indiviuals with disabilities frequently cost little or nothing (See authorities collected in U.S. Commission on Civil Rights, 1983, p. 2). The E. I. du Pont de Nemours and Company has reported: "The cost of most accommodations is nominal" (du Pont, 1981, pp. 17-18). And a U.S. Department of Labor study concluded that accommodation is "no big deal" (DOL, 1982, p. 2).

If the practical application of the reasonable accommodation requirement has not been particularly troublesome, its conceptual and legal theoretical development has been somewhat more problematic. None of the existing handicap nondiscrimination statutes explicitly mention a duty to make reasonable accommodations to permit the participation of handicapped people. The U.S. Supreme Court, in the case of Alexander v. Choate (105 S.Ct. 712 (1985)), recognized the existence of a duty to make reasonable accommodations under Section 504 of the Rehabilitation Act of 1973: "to assure meaningful access, reasonable accommodations in the grantee's program or benefit may have to be made." (Id. at p. 721). The Court noted that "the regulations implementing section 504 are consistent with the view that reasonable adjustments in the nature of the benefit offered must at times be made to assure meaningful access." (Id. at p. 721 n. 21). Nonetheless, the Court's ruling, coupled with its earlier hazy analysis in Southeastern Community College v. Davis (442 U.S. 397, 411-413 (1979)), has not dispelled confusion about the nature and extent of a duty to accommodate. Lower courts, regulatory agencies, and analysts have wrestled very inconsistently with questions about the existence and extent of the reasonable accommodation requirement. Section 504 has been variously interpreted as requiring modifications to existing programs as long as such changes are not "massive," as mandating only "modest affirmative steps" to accommodate persons with disabilities, as requiring only de minimis modifications (those not requiring any effort or expense), or as not requiring accommodation at all.

The absence of a stated requirement of reasonable accommodation and of delineated standards for its application is one of the most serious shortcomings of current handicap equal opportunity laws.

B. Failure to Spell Out Elements of Nondiscrimination

Laws such as Section 504 of the Rehabilitation Act of 1973 prohibit discrimination on the basis of handicap in general terms, but they do not further define or delineate the nature of the "discrimination" that is prohibited. This leaves open a number of key questions about the impact of the nondiscrimination requirement. Is it discrimination to fail to remove architectural, transportation, and communication barriers? How far does the duty to remove such barriers extend? Is it discrimination to use selection criteria and eligibility requirements that screen out or have a disproportionate effect upon people with disabilities? What tests or standards should be applied to determine the legality of such criteria or eligibility requirements? Are there limits upon the changes that a person, business, or agency is required to make in its operations in order to avoid or stop discriminating? To what extent are costs and impact upon a program or activity a defense to the duty not to discriminate? These and other questions about the nature and extent of the handicap nondiscrimination requirement remain largely unanswered and debated, because of the failure of the statutes to resolve them by spelling out the types and elements of the discrimination that is prohibited.

Until the Supreme Court resolved the issue in the recent case of Alexander v. Choate (105 S.Ct. 712 (1985)), it was not even clear whether Section 504 prohibited discrimination that occurs unintentionally, or whether its nondiscrimination mandate was limited only to intentional actions. Looking at such unintentional discrimination as architectural barriers erected thoughtlessly, the Court declared: "much of the conduct that Congress sought to alter in passing the Rehabilitation Act would be difficult if not impossible to reach were the Act construed to proscribe only conduct fueled by a discriminatory intent" (Id. at p. 719). It is noteworthy, however, that litigation had to be pursued to the highest court in the land to answer the question whether Section 504 addresses unintentional acts of discrimination. Clarity and consistency in the interpretation and application of handicap nondiscrimination laws would be greatly furthered by a clear delineation in the statutes themselves of the types of discrimination they make unlawful.

C. Use of the Word "Solely" in Statutory Language

Section 504 of the Rehabilitation Act of 1973 states that no qualified handicapped individual shall be excluded, denied benefits, or subjected to discrimination "solely by reason of his handicap." The phrase "solely by reason of" does not appear in other types of nondiscrimination laws. Whatever may have prompted the choice of this language in drafting the statute, it may be interpreted to allow discrimination, exclusion, and denials of benefits on the basis of handicap where such discrimination is only one of the justifications for the action taken. The goal of such laws would most appropriately seem to be to eliminate from the decision-making process discrimination against persons with disabilities, not to eliminate such discrimination only when it is found in a pristine, isolated, unadulterated form. As in nondiscrimination laws protecting other groups, the phrase "solely by reason of" is unnecessary and should not be included in laws guaranteeing equal opportunities for people with disabilities.

D. Problems With Concept of "Otherwise Qualified"

By its terms, Section 504 applies to handicapped individuals who are "otherwise qualified." The phrase "otherwise qualified" is not found in other types of nondiscrimination laws, presumably because it is assumed that denials of opportunity because of failure to meet legitimate qualifications do not constitute discrimination condemned by these laws. From this point of view, the phrase "otherwise qualified" in Section 504 may be considered a redundancy. A person who is denied a benefit because he or she does not possess the requisite qualifications has not been subjected to discrimination; such an individual has been excluded because of an absence of qualifications, not on the basis of handicap discrimination. On the other hand, if the qualifications established for a job or activity are themselves discriminatory, the concept of "otherwise qualified" in the statute only further complicates the analysis. In each case, the pertinent question under Section 504 would seem to be whether a person has been discriminated against on the basis of handicap. The close interrelationship between the concepts of "otherwise qualified" and discrimination under Section 504 has been noted by the Supreme Court. In Alexander v. Choate, the Court observed that "the question of who is 'otherwise qualified' and what actions constitute 'discrimination' under the Section would seem to be two sides of a single coin..." (Id. at p. 720, n. 19).

The inclusion of "otherwise qualified" in the statutory language leads to results that seem clearly illogical. The outcome of a case in which a handicapped person is found not to possess the appropriate qualifications for a program or activity is a ruling that the person is not an "otherwise qualified handicapped individual," and is, therefore, not protected by Section 504 -- Section 504's prohibition of discrimination does not apply to that person and that individual cannot invoke the statute's protection. A more logical result would seem to be a ruling that a handicapped individual who does not have appropriate qualifications is covered by the nondiscrimination requirement, but has not, in fact, been discriminated against.

The implications of the "otherwise qualified" phraseology were clearly illustrated in the Supreme Court's analysis in Southeastern Community College v. Davis (442 U.S. 397 (1979)). The case involved a woman with a serious hearing disability who had been excluded from a clinical registered nurse training program. The Court determined that there were no modifications that the college could make in its program that would enable Ms. Davis to successfully participate in the program. The logical conclusion, therefore, would have been that Ms. Davis had not been discriminated against. But because of the "otherwise qualified" wording in Section 504, the Court's conclusion instead was that Davis was not an "otherwise qualified handicapped individual," and Section 504 did not cover her. Such an analysis seems to blur a scope of coverage question with a substantive question of discrimination.

For persons with disabilities, the danger of the "otherwise qualified" concept is that by the way agencies state their qualifications for participation in a program or activity covered by Section 504 they can eliminate persons with various disabilities from eligibility, and can even make the disabled person ineligible for the statutory protection against discrimination. This danger is all the more real because, as noted above, the handicap nondiscrimination laws provide no statutory standards regarding the use of discriminatory eligibility requirements, selection criteria, and qualifications standards. Moreover, there has not been a consistent recognition of the interplay between qualifications and reasonable accommodation. Some otherwise unqualified persons may become qualified if reasonable modifications of the program or activity are made. For example, the ability to walk up stairs may be a legitimate qualification for a job in a particular factory, but a person who uses a wheelchair may nonetheless become qualified if the company is required to make a specific work station accessible as part of its duty to make reasonable accommodations to persons with disabilities. The relationship between reasonable accommodation and qualifications and the delineation of what types of qualifications are nondiscriminatory and permissible are part of the overall task of defining and setting standards regarding discrimination. The inclusion of the "otherwise qualified" concept in the statute is unnecessary and problematic, and serves to obscure the real issues.

E. Problems With the Term "Handicapped Individual"

Section 504 protection is afforded to an otherwise qualified "handicapped individual." In delineating a class of persons that is eligible for the protection of the statute, Section 504 deviates from the model of other types of nondiscrimination statutes, which simply prohibit discrimination "on the basis of" race, or sex, or national origin, etc.; all persons are covered by the protection of these other statutes. Under Section 504, before you are protected from discrimination on the basis of handicap, you must first show that you are a "handicapped individual."

For persons with disabilities who have spent many years of their lives stressing their abilities rather than their limitations, and who have strenuously objected to being assigned labels such as "handicapped," the need to prove that one is a "handicapped individual" can be very undesirable. Moreover, the showing that one is "handicapped" often tends to depend upon a medical model of disability -- the necessary proof is often a doctor's certification that the individual has a mental or physical handicap according to medical standards. For many persons with disabilities, this medical approach to disabilities is objectionable.

Some potential problems with the concept of "handicapped individual" have been avoided by the broad definition provided in the statute. For the purposes of Title V of the Rehabilitation Act (which includes Sections 501, 502, 503, 504, and 505), "handicapped individual" is defined as "any person who (A) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (B) has a record of such an impairment, or (C) is regarded as having such an impairment." (29 U.S.C. Section 706). The regulations implementing Section 504 fill in some of the details of this general definition by listing categories of conditions included. An Appendix accompanying the regulations when they were originally published provides even more specificity by giving a partial list of the particular conditions denominated "handicaps" under the definition (42 Federal Register 22685-86 (May 4, 1977)).

The statutory formulation, the regulations, and the analytic Appendix together provide a definitional approach that is expansive and flexible, and yet also fairly specific. The inclusion of the "has a record of" and "is regarded as having" components of the statutory definition could go a long way toward making the definition sufficiently broad and flexible and avoiding a medical cerification approach. Nonetheless, in practical application in administrative proceedings and court cases, persons with disabilities most often find themselves having to prove that they meet criteria (A) of the statutory formulation, i.e., that they have a physical or mental impairment that substantially limits one or more major life activities. Such a requirement does not sit well with those disabled individuals whose orientation is toward achievement and independence.

The statute's denomination of a protected class of "handicapped individuals" also causes problems about where lines should appropriately be drawn for the statute's coverage. Conditions that do not inherently interfere with major life activities may become serious "handicaps" because of employers' and agencies' reactions to them. Individuals have been denied employment and excluded from participation in programs and activities because of such conditions as glaucoma in an arrested state, cancer of the uterus that has been successfully treated, minor degrees of back impairment, a missing kidney, absence of part of a finger, or double vision. Many of these conditions do not of themselves entail a substantial limitation upon major life activities, so a person with such a condition has a hard time meeting the statutory definition for Section 504 protection. Yet they may have been excluded precisely because of discrimination against them on account of their disabilities.

Very often, the "handicapped individual" limitation to Section 504 coverage places a person who has been discriminated against on the basis of handicap in a "Catch 22" situation. To be a "handicapped individual" eligible for Section 504 protection, a person has to show that he or she has a substantial impairment of ability that limits major life activities, but to be "qualified," a person has to show that he or she is not substantially impaired in ability.

Proof of class membership is not required under other types of nondiscrimination laws, and statutes guaranteeing equal opportunity for persons with disabilities need not have such a requirement either. Such laws should focus upon a demonstration of discrimination "on the basis of handicap" rather than requiring proof of membership in a protected class.

F. Lack of a Clear Distinction Between Nondiscrimination and Affirmative Action

Sections 501 and 503 of the Rehabilitation Act of 1973 require Federal agencies and Federal contractors, respectively, to have an "affirmative action" program for the employment and advancement of individuals with disabilities. Section 504 prohibits discrimination on the basis of handicap. As noted previously, the concept of discrimination is not defined in the Act. Likewise, the meaning of the term "affirmative action" is not described or defined. Consequently, there has been some confusion concerning the nature and extent of each of these requirements, and where to draw a line between them.

Such confusion resulting from lack of statutory clarity was

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evident in the opinion of the United States Supreme Court in Southeastern Community College v. Davis, (442 U.S. 397, 410-413 (1979)). The Court tried to draw a distinction between "evenhanded treatment of qualified handicapped persons" and "affirmative efforts to overcome the disabilities caused by handicaps." The former, according to the Court, is nondiscrimination; the latter, affirmative action. And Section 504, unlike Sections 501 and 503, mandates only nondiscrimination, not affirmative action. Such analysis, however, runs into trouble with concepts such as reasonable accommodation and architectural barrier removal. Are these nondiscrimination or affirmative action? In the Davis opinion, the Court first discusses accommodation as an affirmative action requirement and then, two pages later, describes accommodation as a nondiscrimination requirement (442 U.S. 411-13).

The Court subsequently acknowledged the analytic haziness of its opinion in Davis. In Alexander v. Choate, the Court observed:

> Our use of the term affirmative action in this context has been severely criticized for failing to appreciate the difference between affirmative action and reasonable accommodation; the former is said to refer to a remedial policy for the victims of past discrimination, while the latter relates to the elimination of existing obstacles against the handicapped.
> (Id. at p. 721, n. 20)

The statutory lack of definity about the meaning of nondiscrimination and affirmative action has led to inconsistent interpretations of the extent of the duty not to discriminate under Section 504, on the one hand, and to a lack of clarity about requirements to engage in recruitment and outreach efforts under Sections 501 and 503, on the other. To establish clear and enforceable standards, equal opportunity laws for people with disabilities should define the elements of nondiscrimination, as discussed above, and should explicitly require recruitment and outreach activities to increase the participation of people with disabilities in programs and activities covered by these laws.

G. Problems With the Enforceability of Section 503

The requirement imposed by Section 503 of the Rehabilitation Act of 1973 that Federal contractors take affirmative action to employ and advance qualified handicapped individuals is enforceable by the filing of a complaint with the Department of Labor (DOL). Administrative enforcement proceedings within DOL have sometimes been criticized as involving lengthy delays and reluctance upon the part of the Department to rule against contractors.

Section 503 does not mention any right of aggrieved handicapped persons to file a private court suit against a contractor who has violated the statute. Some courts have ruled that such a private right of action is implicitly created by Section 503, but the greater weight of judicial precedent is against the existence of such a right.

In accordance with other types of nondiscrimination laws, it seems appropriate that if a disabled complainant has filed a complaint with the Department of Labor and has not obtained any administrative resolution within a reasonable period of time, the complainant should have the option of filing a Federal court lawsuit to vindicate his or her rights under the law. The right to such a private cause of action should be explicitly provided in the statute.

H. Limited Applicability of Barrier Removal Requirements and Problems Regarding the Architectural and Transportation Barriers Compliance Board

Section 502 of the Rehabilitation Act of 1973 established the Architectural and Transportation Barriers Compliance Board (ATBCB) and charged it with a variety of responsibilities in regard to the enforcement of the Architectural Barriers Act (42 U.S.C. Sections 4151-4157), and the elimination of architectural, transportation, and communication barriers confronting individuals with disabilities.

The Architectural Barriers Act of 1968 was the first Federal legislation requiring certain Federally constructed, altered, leased, or financed buildings to be readily accessible to persons with physical disabilities. It designated four agencies -- the General Services Administration, the Department of Defense, the Department of Housing and Urban Development, and the U.S. Postal Service -- to develop standards for the design, construction, and alteration of buildings covered by the Act.

A 1978 amendment to Section 502 of the Rehabilitation Act added to the ATBCB's functions the responsibility to issue minimum guidelines and requirements for the standards established by the four standard-setting agencies. A final rule issued by ATBCB establishing such Minimum Guidelines was published in the Federal Register on August 4, 1982 (42 Federal Register 33862, codified at 36 C.F.R. Part 1190). Subsequently, the four standard-setting agencies concurred in the joint issuance of Uniform Federal Accessibility Standards, which were published on August 2, 1984.

A significant problem with Federal requirements regarding architectural, transportation, and communication barriers removal is simply that most buildings and transportation systems are not subject to such requirements. The buildings subject to regulation under Federal accessibility standards are primarily only those that are built by, leased by, altered by, or financed by the Federal government. While this obviously includes a large number of buildings, a much larger number of buildings continue to be built without being subject to any accessibility requirements. Moreover, even for those buildings that are subject to Federal barriers laws, the limited resources of ATBCB and the limited enforcement efforts of the four standard-setting agencies result in sporadic implementation of accessibility requirements. Likewise, existing state and local laws regarding architectural barriers are seldom enforced.

Many commentators and architects have begun to advocate a concept of "universal accessibility." They argue that mandates of accessible building design would be beneficial to most Americans. As one architect has written:

> (A)ll people pass through stages of ability and disability: children who have not yet attained adult strength, stature or mental processes; pregnant women who, even without complications, suffer reduced stamina, mobility, agility and balance; persons who tend the very young and are encumbered by carrying infants, maneuvering baby vehicles or moving hand-in-hand with a toddler whose mobility is tenuous at best; aging persons who are subject to progressive loss of physical, perceptual and mental faculties. In addition, there are the many people who at a given time may experience temporary disabilities as a result of illness or accidental

> mishap. The designed environment at present satisfactorily accommodates only a small number of people who are in their prime period of the life cycle and who also possess maximum physical and mental capabilities. All the rest of us who are in the majority could benefit greatly from barrier-free design.
> (Morgan, pp. 50-51)

The benefits of universal accessibility, when combined with data that indicate the costs of achieving barrier-free design in new construction is less than 1 percent, make for a strong argument in favor of broad accessibility requirements. The Federal government should make use of its authority to enforce the Fourteenth Amendment, to regulate interstate commerce, and to regulate recipients of Federal financial assistance, to establish broad and strong standards for the elimination of architectural, transportation, and communication barriers.

A more specific problem with the coverage of Federal accessibility requirements concerns the authority of the ATBCB in regard to transportation barriers. A 1978 amendment to Section 502 gave ATBCB the responsibility to "insure that public conveyances, including rolling stock, are readily accessible to, and usable by, physically handicapped persons." The statute does not, however, expressly provide that ATBCB has authority to establish minimum guidelines for transportation facilities and vehicles analagous to its authority to write minimum guidelines for buildings subject to the Architectural Barriers Act. As a result, the ATBCB's authority in the area of public conveyances is somewhat unclear, and the Board has not assumed a very strong role in setting standards for making public conveyances accessible.

Another problem with the ATBCB relates to the statutory language regarding its composition and terms of offices of its members. As established in Section 502, the Board is to consist of ten Federal agency heads (or their high-level designees), and eleven public, non-governmental members (including five handicapped individuals). The terms of office for the public members is set at three years. Unlike many other similar pieces of legislation establishing boards and commissions, Section 502 does not say that a member shall continue to serve until a successor has been selected and appointed. As a result, for much of its existence ATBCB has had unfilled vacancies in the public member positions. These vacancies have undercut the public member majority on the Board as contemplated in the language of the Act. The terms of office provisions of Section 502 should track other statutes and require members to continue to serve until successors have been appointed and are ready to serve on the Board.

I. EEOC Authority For Enforcement Under Section 501

As originally enacted, Section 501 of the Rehabilitation Act of 1973 required executive agencies to submit affirmative action program plans to the Civil Service Commission, and directed the Commission to review such plans to see if they provide sufficient assurances, procedures, and commitments to achieve employment opportunities for people with disabilities. Pursuant to Reorganization Plan No. 1 of 1978 (43 Federal Register 19807), all enforcement functions related to employment of handicapped individuals previously held by the Civil Service Commission were transferred to the Equal Employment Opportunity Commission

(EEOC). Pursuant to this transfer of authority, EEOC has issued regulations for the implementation of Section 501 (29 C.F.R. part 1613, subpart G) and has administered the affirmative action plan review process.

In 1984 amendments to the Rehabilitation Act, a technical amendment to Section 501 was made, apparently prompted by the fact that the statute still made reference to the defunct Civil Service Commission. Inadvertently, however, the reference was changed to the Office of Personnel Management, which was the successor to many other Civil Service Commission functions, rather than to the EEOC. That there was no Congressional intent to transfer Section 501 enforcement functions away from EEOC is confirmed by the fact that Congress ratified the provisions of Reorganization Plan No. 1 of 1978 subsequent to the Section 501 amendment. Nonetheless, the erroneous amendment is confusing and should be corrected. Moreover, the mandate of Section 501 should be strengthened to require not merely the submission of an affirmative action plan but the submission and implementation of such a plan, and EEOC should explicitly be given the responsibility for establishing regulations outlining appropriate outreach and recruiting activities, in addition to nondiscrimination standards.

J. Application to Discrimination in Medical Treatment

One result of the controversy and legal actions surrounding the highly publicized instances of denials of medical treatment to certain handicapped newborns -- the so-called Baby Doe cases -- was the decision of a United States Circuit Court of Appeals that Section 504 of the Rehabilitation Act of 1973 does not apply to medical treatment decisions. In the case of United States v. University Hosp., State U. of New York (729 F.2d 144 (2d Cir. 1984)) (commonly referred to as the "Baby Jane Doe" or "Stony Brook" case), the Court of Appeals for the Second Circuit ruled that there had traditionally been a "consistent congressional policy against the involvement of federal personnel in medical treatment issues" (Id. at p. 160). In light of this policy, the court held that it would not impute a Congressional intent that Section 504 apply to medical treatment issues in the absence of clearly expressed legislative intent to that effect. The court also expressed some difficulty with the question whether a handicapped child is a "handicapped individual" under Section 504, but ultimately determined that it "would defy common sense" to rule otherwise.

The court's ruling that Section 504 does not apply to discrimination in medical treatment removes the protection of the statute from a very important area. The U.S. Commission on Civil Rights has found that people with disabilities "face discrimination in the availability and delivery of medical services," citing examples of medical experimentation on disabled people, electroshock treatments, administration of psychotropic drugs, psychosurgery, inappropriate organ transplants, and denials of routine medical care, in addition to denials of lifesaving medical treatment to newborns with disabilities (U.S. Commission on Civil Rights, 1983, at pp. 35-36).

The decision in the University Hospital case has been appealed to the United States Supreme Court. Unless the matter is clarified by the high Court, the coverage of medical treatment by equal opportunity laws for disabled people should be reestablished in the statutory language.

K. Other Enforcement Problems With Section 504

In addition to problems already mentioned in regard to the implementation of Section 504 of the Rehabilitation Act of 1973, there have been numerous delays in the regulatory enforcement process under Section 504. Regulations have been very slow in coming forth from agencies with Section 504 responsibilities. In 1980, a Federal court lawsuit, Williams v. United States (No. 80-5368 (C.D. Cal., filed Dec. 3, 1980)) was filed to address the failure of Federal agencies to promulgate regulations regarding their programs and activities.

There have also been criticisms of a Department of Justice Prototype Regulation issued to provide guidance to agencies in preparing their regulations, and of the proposed regulations issued by some agencies, particularly in regard to limitations upon agency obligations under the regulations.

Most of the substantive problems with the Prototype and agencies' proposed regulations result from a lack of specificity and standards in the statute, as discussed previously. A statutory clarification of the nondiscrimination requirement, along with timelines for the issuance of implementing regulations, would go a long way toward resolution of implementation problems under Section 504.

IV. PROBLEMS IN TRYING TO APPLY TRADITIONAL CIVIL RIGHTS LEGAL STANDARDS TO DISCRIMINATION ON THE BASIS OF HANDICAP

Statutes prohibiting discrimination on the basis of handicap have been considered "part of the general corpus of discrimination law" (New York State Ass'n for Retarded Children v. Carey, 612 F.2d 644, 649 (2d Cir. 1979)), and analysts, courts, and regulators have looked to interpretations of traditional civil rights laws when analyzing and applying equal opportunity laws for people with disabilities. It has become apparent, however, that there are limits to the applicability of principles developed in these other areas to the problems of discrimination against people with disabilities. The U.S. Commission on Civil Rights has cautioned that legal approaches developed in race, sex, national origin, and religious discrimination cases cannot be applied uniformly and mechanically to cases of discrimination on the basis of handicap: "The legal theories, principles, and precedents of traditional civil rights law should be applied to handicap discrimination cases only when, and to the degree that, they are equally relevant." (U.S. Commission on Civil Rights, 1983, pp. 149, 163). The American Coalition of Citizens with Disabilities, in testimony endorsed by the American Council of the Blind, the Association for Retarded Citizens, the Association of Children with Learning Disabilities, the Disability Rights Center, the National Easter Seal Society, the Paralyzed Veterans of America, the National Network of Learning Disabled Adults, and the National Association of Private Residential Facilities for the Mentally Retarded, and submitted to the Subcommittee on

Employment Opportunities of the House Committee on Education and Labor on June 6, 1985, declared that "existing standards of nondiscrimination under Title VI of the Civil Rights Act of 1964 as applied to race, sex, religion and national origin are either inadequate or inappropriate to address discrimination on the basis of handicap..." A Federal court has observed that trying to fit the problem of handicap discrimination into the standards and remedies developed to deal with other types of discrimination is "akin to fitting a square peg into a round hole." (Garrity v. Gallen, 522 F.Supp. 171, 206 (D.N.H. 1981))

One major way in which standards of equal opportunity for persons with disabilities differ from those developed for other groups is the concept of reasonable accommodation. The individualized matching of persons with activities and making modifications to the activity to enable the individual to participate is integral to eliminating discrimination on the basis of handicap, but such matching and modification is rarely required in addressing other types of discrimination. The term "reasonable accommodation" does appear in Title VII of the Civil Rights Act of 1964 (42 U.S.C. Section 2000e(j)) in regard to employers' obligation to accommodate the needs arising from religious practice. The Supreme Court has ruled, however, that this religious accommodation provision imposes only a de minimis requirement (Trans World Airlines v. Hardison, 432 U.S. 63, 84 (1977)), so it is not analagous to the matching and modification process that characterizes reasonable accommodation for persons with disabilities.

Similarly, other areas of nondiscrimination law have no direct analog to the requirement of removing architectural, transportation, and communication barriers. Discrimination against people with disabilities has literally been built into the physical environment, and eliminating such discrimination requires planning and action to remove barriers that exclude disabled people. In the case of Alexander v. Choate (105 S.Ct. 712 (1985)), the U.S. Supreme Court recognized that removing architectural and transportation barriers is of pivotal importance in eliminating discrimination against people with disabilities (Id. at p. 719). In discussing the nondiscrimination requirements of the Rehabilitation Act of 1973, the Court stated that "elimination of architectural barriers was one of the central aims of the Act" (Id. at p. 719). Such environmental barriers resulting in the physical exclusion of a group of people are not a major feature of nondiscrimination standards under other types of laws.

Another difference between legal standards for addressing discrimination against people with disabilities and other types of discrimination relates to eligibility requirements, qualifications standards, and selection criteria. Under traditional civil rights standards, any such requirements, standards, and criteria that are based upon a person's race, sex, religion, or national origin (or that use some criteria as a subterfuge for race, sex, religion, or national origin) are generally illegal. In employment, the use of criteria of religion, sex, or national origin may be justified only by demonstrating that they are a bona fide occupational qualification (BFOQ) "reasonably necessary to the normal operation of that particular business or enterprise..." (42 U.S.C. Section 2000e-2(e)). Courts have indicated that the BFOQ defense is to be very narrowly and stringently applied. There is no BFOQ defense for employment discrimination on the basis of race. In short, race, sex, national origin, and religion are almost never legitimate criteria for decisions about whether to allow a person to have a job or participate in a program or activity, because such characteristics have no direct connection with ability to perform or participate.

With disabilities, on the other hand, there is a much more complex relationship between a particular person's disability and performance ability. Some judgments based upon disability may be appropriate, while others may be discriminatory. A vision requirement for an air traffic controller position (with current technology) may be a necessary eligibility restriction, but the exclusion of blind people from employment as lawyers or insurance salespersons might constitute discrimination. A deaf person should be eligible to compete for a job as a construction worker or an accountant, but might appropriately be denied a position as a voice coach or a sound technician. The distinctions between these situations largely depend upon an analysis of the essential elements of a job, program, or activity, and a determination whether, with reasonable accommodation, the person can participate and perform the essential elements. Consequently, a more complex set of standards are required to deal with eligibility requirements, selection criteria, and qualifications standards in relation to disabilities.

For these and other reasons, the standards for resolving problems of discrimination against persons with disabilities must differ from those addressing other types of discrimination. As the American Coalition of Citizens with Disabilities and eight other national disability organizations have stated:

> it is our conclusion that current Title VII standards are not adequate to effectively address and remedy discrimination on the basis of handicap. The necessity for expanding the scope of coverage of handicap discrimination laws to make them coextensive with the coverage of other civil rights laws should be pursued in a manner which guarantees that the legal standards to be applied will be tailored to provide clear and effective remedies to the types of discrimination faced by Americans with disabilities.
> (ACCD, 1985, at p. 8)

V. BILL OF RIGHTS FOR PERSONS WITH DISABILITIES

In some situations, particularly in the context of large residential institutions, disabled people have had to give up many of their rights and basic freedoms in order to obtain needed services, treatment, and benefits. Concerns that service providers and public agencies have sometimes run roughshod over the rights of their clients have prompted calls for bills of rights to proclaim and protect the rights of citizens with disabilities. In the Developmental Disabilities Assistance and Bill of Rights Act of 1975 (42 U.S.C. Section 6000 *et seq.*), Congress created such a bill of rights for developmentally disabled persons. Section 6010 of the Act is a Congressional finding that persons with developmental disabilities possess a list of rights; the rights enumerated include a right to appropriate treatment, services, and habilitation, to be provided in the least restrictive alternative, and a requirement that institutional and other residential programs meet certain minimum standards:

> (i) Provision of a nourishing, well-balanced daily diet to the persons with developmental disabilities being served by the program.
> (ii) Provision to such persons of appropriate and sufficient medical and dental services.
> (iii) Prohibition of the use of physical restraint on such persons unless absolutely necessary and prohibition of the use of such restraint as a punishment or as a substitute for a habilitation program.
> (iv) Prohibition on the excessive use of chemical restraints on such persons and the use of such restraints as punishment or as a substitute for a habilitation program or in quantities that interfere with services, treatment, or habilitation for such persons.
> (v) Permission for close relatives of such persons to visit them at reasonable hours without prior notice.
> (vi) Compliance with adequate fire and safety standards...

Section 6010 also requires compliance with regulations providing standards for intermediate care facilities for mentally retarded people, and, for facilities not covered by the ICFMR standards, it requires that appropriate care be provided, that only persons whose needs can be met by a facility be admitted to that facility, and that residential programs "provide humane care of the residents of the facilities, are sanitary, and protect their rights."

Despite the strong wording of the Section and the fact that Congress headed the Title of the Act in which Section 6010 is found "Establishment and Protection of the Rights of Persons with Developmental Disabilities," the Supreme Court determined that Congress did not intend to create enforceable rights and obligations. In Pennhurst State School and Hospital v. Halderman (451 U.S. 1 (1981)), the Court ruled that in enacting the Bill of Rights Congress was simply "encouraging" or giving a "nudge in the preferred direction," rather than mandating compliance with the rights enumerated. It held that Section 6010 "does no more than express a congressional preference for certain kinds of treatment" and is, thus, "too thin a reed to support the rights and obligations read into it." To date, Congress has taken no action to reestablish the enforceability of the rights declared in the Developmental Disabilities Bill of Rights.

In 1978, the Task Panel on Legal and Ethical Issues of the President's Commission on Mental Health submitted its report on Mental Health and Human Rights, in which it called for the establishment of Bills of Rights for all mentally handicapped persons, both those institutionalized and those residing in the community (Task Panel Report, 20 Ariz. Law Review at pp. 133-137). The Panel noted that approximately 14 states had established Bills of Rights for psychiatric patients and 12 had similar legislation for mentally retarded persons. It concluded that an adequate Bill of Rights should include at least seven basic components:

> (a) A statement that all mentally handicapped persons are entitled to the specified rights;
> (b) A statement that rights cannot be abridged solely because of a person's handicap or because s/he is being treated (whether voluntarily or involuntarily);
> (c) A declaration of the right to treatment, the right to refuse treatment and the regulation of treatment, the right to privacy and dignity, the right to a humane physical and psychological environment and the right to the least restrictive alternative setting for treatment;
> (d) A statement of other, enumerated fundamental rights which may not be abridged or limited;
> (e) A statement of other specified rights which may be altered or limited only under specific, limited circumstances;
> (f) An enforcement provision; and
> (g) A statement that handicapped persons retain the right to enforce their rights through habeas corpus and all other common law or statutory remedies.
> (Task Panel Report at p. 134)

Noting that existing state Bills of Rights are almost completely lacking in enforcement mechanisms, the Panel concluded that "(t)he statute should contain a strong enforcement provision" (Task Panel Report at p. 137).

A bill introduced in the 99th Congress (Senate Bill 974) would establish a Bill of Rights for mentally ill persons comparable to the Bill of Rights for developmentally disabled people. It contains no stronger enforceability language than the developmental disabilities version, and would presumably be unenforceable pursuant to the Court's reasoning in the Pennhurst decision.

If such Bills of Rights are to be anything more than empty promises, they should be made binding and enforceable. And if an enforceable Bill of Rights is to be enacted, there do not appear to be any good reasons for not expanding it beyond developmental disabilities or mental disabilities to establish and protect the rights of all Americans with disabilities.

VI. INFORMATION ABOUT RIGHTS AND LEGAL REPRESENTATION

The Task Panel on Legal and Ethical Issues of the President's Commission on Mental Health aptly observed that "recognition of rights precedes enforcement" (Task Panel Report at p. 138). The laws guaranteeing equal opportunity for persons with disabilities recommended in this report will have little effect unless people with disabilities learn about such laws, their meaning, and how to go about enforcing them. To assure that persons with disabilities will have access to information about their substantive and procedural rights, it will be important for agencies charged with enforcing the laws and regulations to publicize their requirements, and to seek to inform disabled people and their families about these requirements and the rights of individuals who believe that such requirements have been violated. It will also be important to encourage independent living centers, consumer and parent organizations, and agencies providing advocacy services, to provide accurate information about the rights of people with disabilities under Federal laws, regulations, and court decisions, and about the avenues of potential remedies one may pursue to vindicate such rights when you believe they have been violated.

Frequently, asserting one's rights through the pursuit of legal and administrative remedies leads a person with a disability to need legal representation. For many Americans who are not wealthy, adequate legal representation is not easy to obtain, particularly in a specialized field such as that of disability rights law. Access to competent legal representation may be an essential prerequisite for making legal guarantees of equal opportunity for people with disabilities a reality.

The Developmental Disabilities Assistance and Bill of Rights Act of 1975 required each state to establish "a system to protect and advocate the rights of persons with developmental disabilities" (42 U.S.C. Section 6012), The statute specifies further that these protection and advocacy systems (P&As) must "have the authority to pursue legal, administrative, and other appropriate remedies" to insure the protection of the rights of developmentally disabled persons. As to the importance of such advocacy efforts, a 1980 report of the General Accounting Office concluded that "the State Protection and Advocacy Program could be the most potent and effective mechanism to insure that the developmentally disabled receive the benefits, services, and rights they are entitled to." (GAO, 1980, p. 72) A report prepared by the Institute for Comprehensive Planning found that P&As had served some 44,000 developmentally disabled persons during their first two years of operation (Henney and Alldredge, 1980, p. 3), with only a small percentage of the cases necessitating legal action. The report indicated that only 1.5% of the cases handled by P&As during the two year period involved actual court proceedings, and another 5.5% required other types of formal proceedings such as administrative hearings and due process hearings. (Id. at p. 12)

A bill currently pending in Congress (Senate Bill 974) would create a similar protection and advocacy system for mentally ill persons. Such advocacy services should be made available for all citizens with disabilities, whatever their category of disablity and regardless of the age of onset of their disabling condition.

Another important determinant of the ability of people to obtain appropriate legal redress for denials of their rights is the availability of awards of attorneys fees. Court awards of reasonable attorneys fees to successful complainants are authorized under most other types of nondiscrimination laws. Currently, attorneys fees are available under Sections 504 and 505 of the Rehabilitation Act of 1973. They are not, however, available under the Education for All Handicapped Children Act (Public Law 94-142), pursuant to the decision of the United States Supreme Court in the case of Smith v. Robinson (104 S.Ct. 334 (1984)). Bills have been introduced in Congress to undo the impact of Smith v. Robinson and authorize the award of reasonable attorneys fees when parents prevail in special education cases.

As under most other types of nondiscrimination statutes, equal opportunity laws for people with disabilities should provide for reasonable attorneys fees to be awarded when complainants successfully prove that they have been the victims of unlawful discrimination.

VII. TECHNICAL ASSISTANCE AND AID TO SMALL BUSINESSES

In many ways Big Business has already endorsed the concept of equal opportunities for people with disabilities and has begun efforts to pursue this goal. David T. Kearns, the President of Xerox Corporation, has been a leading spokesperson for "full participation" for citizens with disabilities, arguing that business has an economic stake in helping individuals with disabilities become employed and in taking advantage of the talent pool they represent (Gatty, p. 3). E.I. du Pont de Nemours and Company has made a point of recruiting disabled employees and has monitored their numbers and progress in the company. Du Pont has achieved a reputation as an exemplary employer of people with disabilities, and the company's reports are replete with examples of successful case stories (Du Pont, 1981, pp. 10-16). In addition to Xerox and Du Pont, other major companies making similar efforts to promote the employment of persons with disabilities include AT&T; the Prudential Insurance Company; Sears, Roebuck and Company; Levi Strauss and Company; IBM; and Control Data Corporation, to name but a few (Gatty, pp. 30-35). Recently, Levi Strauss and McDonald's were among the companies whose national television advertising campaigns have featured people with disabilities in a natural, positive context.

Companies with government contracts have had some dozen years experience with the requirement that they "take affirmative action to employ and advance in employment qualified handicapped persons" as mandated in Section 503 of the Rehabilitation Act of

1973. Likewise, universities and other major Federal grant recipients have been subject to the Section 504 nondiscrimination requirement since 1973. To these agencies, equal opportunities for people with disabilities is not a new idea.

Small businesses are likely to have less familiarity with concepts of nondiscrimination on the basis of handicap, barrier removal, and reasonable accommodation, and may have concerns about the feasability of making modifications in their facilities and operations to provide equal opportunities for individuals with disabilities. Data suggests that most such concerns are misplaced; studies of Federal contractors subject to Section 503 indicate that accommodations are usually minor and inexpensive (Ellner and Bender, 1980, pp 51-52; Berkeley Planning Associates, 1982, pp. 20-29; U.S. Commission on Civil Rights, 1983, pp. 106-107). A 1982 United States Department of Labor study of accommodations provided for disabled workers by Federal contractors showed that only 22 percent of such workers received some form of accommodation, and these were generally inexpensive -- half of the accommodations cost nothing and more than two-thirds cost less than $100 (Berkeley Planning Associates, 1982, pp. 20-29). Only about 9 percent involved modifying office equipment, such as telephones or typewriters, or providing dictaphones, audiovisual aids, or other special devices.

Small businesses need to have access to information about the most practical and efficient ways to modify their facilities and practices to permit the participation of disabled persons. They also need to be apprised of information about such programs as the Targeted Jobs Tax Credit and the tax deduction for barrier removal expenses that may help to defray some of the financial impact of necessary modifications. In short, small businesses should be provided with information and technical assistance concerning their responsibilities to provide equal opportunities for people with disabilities in the most practical and efficient manner possible. One program that has begun to address such needs is the Job Accommodations Network. As the scope of equal opportunity laws for people with disabilities is expanded, more such efforts are needed.

Additional programs are also needed to provide funding and incentives for the costs of modifications and barrier removal. These might consist of a direct funding or grant program, a loan fund, guaranteed loans, or tax incentives. Novel sources of funds for such programs might include fines assessed against discriminators or direct transfers of funds saved by Federal agencies when a disabled person gets a job (similar fund transfers for rehabilitation costs are currently made by the Social Security Disability Trust Fund).

Tax incentives might expand upon the current tax deduction for expenses of barrier removal, build upon the Targeted Jobs Tax Credit program, or provide a new program of deductions or tax credits for costs incurred to allow persons with disabilities to be hired or obtain goods and services from small businesses.

VIII. RECOMMENDATIONS

For all the reasons set out in this report, the National Council on the Handicapped makes the following recommendations:

1. Congress should enact a comprehensive law requiring equal opportunity for individuals with disabilities, with broad coverage and setting clear, consistent, and enforceable standards prohibiting discrimination on the basis of handicap.

   Such a statute should be packaged as a single comprehensive bill, perhaps under such a title as "The Americans with Disabilities Act of 1986." The recommendations which follow spell out more specifically the components which such a bill should contain in order to create a comprehensive and effective equal opportunity law for individuals with disabilities.

2. The law should prohibit discrimination on the basis of handicap by:

   a. The Federal Government, all of its agencies and departments, and the United States Postal Service.

   b. All recipients of Federal financial assistance, with coverage of all operations of the recipient and not just a particular program or activity.

   c. Federal contractors and subcontractors and Federal licensees.

   d. All employers engaged in an industry affecting commerce who have fifteen or more employees; employment agencies; and labor unions.

   e. All sellers, landlords, and other providers of housing covered by Title VIII of the Civil Rights Act of 1968.

   f. All public accommodations covered by Title II of the Civil Rights Act of 1964.

   g. All persons, companies, and agencies that engage in the business of interstate transportation of persons, goods, documents, or data.

h. All persons, companies, and agencies that make use of the mails or interstate communications and telecommunications services for the business of selling, arranging, or providing insurance.

i. The States, counties, and local governments, pursuant to Congressional authority to enact legislation that abrogates the States' immunity under the Eleventh Amendment in order to enforce the Fourteenth Amendment guarantee of Equal Protection of the Laws.

These provisions would expand coverage of equal opportunity law for people with disabilities to make it commensurate with the coverage of other types of nondiscrimination laws. In addition, they would undo limitations imposed upon the coverage of such laws as a result of such Supreme Court decisions as Atascadero State Hospital v. Scanlon, Grove City College v. Bell, and Community Television of So. Cal. v. Gottfried. In response to the Scanlon ruling, the coverage of State, county, and local governments (including such entities as local zoning boards) would be spelled out, pursuant to the authority of Congress to abrogate the States' immunity under the Eleventh Amendment in order to enforce the Fourteenth Amendment. In contrast to the Grove City decision, all operations of Federal financial aid recipients would be prohibited from discriminating. And in response to the Gottfried holding, Federal licensees would explicitly be covered. The recommended provisions would also close certain other gaps in the coverage of such statutes by explicitly covering interstate transportation and discriminatory insurance practices.

3. The law should provide a clear definition and standards for applying the prohibition of discrimination on the basis of handicap.

The statute should straightforwardly prohibit "discrimination on the basis of handicap," without establishing any eligibility classification for the coverage of the statute. Discrimination on the basis of handicap should be broadly construed to apply the requirements of the statute to all situations in which a person is subjected to unfair or unnecessary exclusion or disadvantage because of some mental or physical impairment, perceived impairment, or history of impairment. Discrimination should be defined to include: a) Intentional exclusion; b) Unintentional exclusion; c) Segregation; d) Unequal or inferior services, benefits, or activities; e) Less effective services, benefits, or activities; and f) The use of screening criteria with a disparate impact upon individuals with disabilities that do not correlate with actual ability. The nondiscrimination requirement should expressly include a duty to make reasonable accommodations, which should be defined as providing or modifying devices, services, or facilities, or changing practices or procedures in order to allow a particular person to participate in a particular program, activity, or job. The duty not to discriminate should also include an obligation to remove architectural, transportation, and communication barriers, including meeting the accessibility requirements recommended below. In addition, there should be a requirement of eliminating discriminatory qualifications standards, selection criteria, and eligibility requirements, with a delineation of the standards and legal tests to be used to determine when such qualifications, criteria, and requirements constitute discrimination. In addition, a requirement of outreach and recruitment efforts should be explicitly established; the focus of such efforts should be upon people with serious disabilities, such as the Equal Employment Opportunity Commission's current listing of "targeted disabilities."

4. The law should delineate specific enforcement standards, procedures, and timelines for the implementation of equal opportunity requirements.

The agencies responsible for developing regulations implementing the equal opportunity law for people with disabilities should be clearly designated, and timelines established for the issuance, after public comment, of such regulations. The Architectural and Transportation Barriers Compliance Board should be directed to establish binding minimum guidelines for architectural, transportation, and communication accessibility, as discussed below in Recommendation 5. Consistent with such minimum guidelines, the Department of Housing and Urban Development should be directed to develop appropriate regulations concerning housing opportunities (for further discussion, see the Council's report on Housing), the Department of Transportation should be directed to develop regulations for mass transit, air travel, and other modes of transportation covered by the law (for further discussion, see the Council's report on Transportation), the Federal Communications Commission should be directed to promulgate regulations governing its licensees, and other agencies should be directed to develop regulations for the areas of their responsiblity, including the programs and activities they conduct, those they license, and those for which they provide financial assistance. The Equal Employment Opportunity Commission should expressly be charged with the development of regulations governing Federal government employment and for setting standards for all other employment covered by the law. An administrative enforcement process should be provided for individuals who believe that their rights under the law and regulations have been violated. Successful complainants should be entitled to injunctive relief, monetary damages, and back pay as necessary to remedy the discrimination to which they have been subjected. A private right of action in Federal court should be established for complainants if administrative enforcement has not occurred after a specified amount of time (e.g., 60 or 90 days), and at the completion of the administrative decision-making and appeals process. The law should authorize the imposition of fines or the cutoff of Federal funds (including both grants and contracts) if there is a showing of discrimination in an appropriate administrative or judicial proceeding; such fines or funding cutoff should continue until the discrimination is corrected or discontinued.

5. The Architectural and Transportation Barriers Compliance Board should be given the authority and responsibility to issue minimum guidelines for universal accessibility and other standards for the removal of architectural, transportation, and communication barriers in facilities, vehicles, programs, and activities covered by the equal opportunity law for people with disabilities.

This recomendation is intended to correct the problems with the language of Section 502 of the Rehabilitation Act of 1973 as currently worded that have left questions about the extent of ATBCB's authority to set minimum guidelines regarding transportation and communication barriers. It would also expand the Board's authority commensurate with the expanded coverage of the equal opportunity law recommended in this report. Provisions establishing ATBCB should also be amended to provide that public members of the Board shall continue to serve at the expiration of their terms, until their successors have been appointed and are ready to serve.

6. The law should direct the Federal Government to use its leverage as a consumer of goods and services to set standards and timelines for requiring that businesses and companies from which it purchases or rents goods, services, or facilities shall make such goods, services, and facilities accessible, available to, and usable by people with disabilities on a nondiscriminatory basis.

This requirement and standards implementing it should apply to such matters as the rental of conference and meeting rooms; the rental of hotel rooms for government employees and meeting attendees; airline and train tickets, and contracts with airlines and train companies; and rental and leased cars and contracts with rental car and leasing companies. The standards to be imposed in regard to accessibility and usability of facilities and vehicles should be developed by the Architectural and Transportation Barriers Compliance Board, and requirements regarding consumer products and services should be developed and administered by the General Services Administration, in consultation with the ATBCB and the National Council on the Handicapped.

7. Equal opportunity obligations upon Federal contractors and subcontractors should be made enforceable by a private right of action.

This recommendation highlights a change that is implicit in Recommendation 4. It would correct the current situation in which responsibilities of Federal contractors and subcontractors under Section 503 of the Rehabilitation Act of 1973 are sometimes difficult to enforce administratively and are generally held to be unenforceable in the courts.

8. The law should apply to discrimination in medical services.

This provision is necessary to correct the narrowing of coverage resulting from the Court of Appeals decision in *United States v. University Hosp., State U. of New York*, which ruled that Section 504 of the Rehabilitation Act of 1973 does not cover discrimination in the area of medical treatment.

9. An enforceable Bill of Rights for Persons with Disabilities should be enacted.

Because American guarantees of basic rights of all persons in the U.S. Bill of Rights and other constitutional and statutory provisions have not always been equally recognized and implemented in regard to citizens with disabilities, an explicit delineation of important rights of persons with disabilities is necessary to prevent abuses and reestablish those rights. Such a Bill of Rights should be patterned upon the provisions of the existing Developmental Disabilities Bill of Rights and that proposed by the Task Panel on Legal and Ethical Issues of the President's

Commission on Mental Health. It should, however, apply to persons with all types of disabilities, and should explicitly be made enforceable administratively and in the Federal courts.

10. To assure the recognition and implementation of the rights established in this equal opportunity law, Congress should authorize an expanded Protection and Advocacy System in each State to protect and advocate for the rights of individuals with all types of disabilities, regardless of the age of onset; Congress should authorize the awarding of reasonable attorneys fees and litigation expenses to prevailing complainants.

Federal agencies charged with implementing the requirements of the equal opportunity law for persons with disabilities should provide notices and public education efforts to make persons with disabilities and their families, and persons and agencies subject to the nondiscrimination requirement aware of rights and responsibilities under Federal laws, regulations, and court decisions, and of potential remedies and compliance procedures when a violation is alleged. Independent living centers, consumer and parent organizations, service providers, information and referral services, and advocacy agencies should also be encouraged to make such information available. Congress should support additional advocacy services to implement the law by expanding the function of existing developmental disabilities Protection and Advocacy Systems to authorize them to serve persons with all types of physical and mental disabilities and by providing seed money for legal representation to Independent Living Centers and other agencies (perhaps with funds obtained from fines paid by violators of the equal opportunity law). The allowance of reasonable attorneys fees would track other types of nondiscrimination laws that provide for court awards of reasonable attorneys fees to complainants who successfully prove that they have been the victims of illegal discrimination.

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TOPIC PAPER B:

EMPLOYMENT

National Council on the Handicapped

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ACKNOWLEDGMENT

This is one of a series of ten topic papers developed by the National Council on the Handicapped as part of its Special Report to the President and Congress: TOWARD INDEPENDENCE: An Assessment of Federal Laws and Programs Affecting Persons with Disabilities--With Legislative Recommendations. The members of the National Council on the Handicapped wish to expressly acknowledge with appreciation the special contribution made to this paper by Ethel D. Briggs and Naomi Karp.

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I. INTRODUCTION

Employment is an essential key to successful adult integration into community life. Various forms of work are associated with greater independence, productivity, social status, and financial security. Success and quality of life are often measured in terms of paid employment.

Persons with disabilities account for approximately one-sixth of the nation's population. According to the 1980 census, approximately 22.7 million working age Americans (ages 16-64) have physical or mental disabilities that limit employment. Of that number, 15.1 million reported disabilities that prevented them from working. At the time of the Census Survey, 4.6 million (or 20%) of the 22.7 million persons reporting a work disability were employed in the labor market. The number of unemployed persons with a work disability amounted to 0.6 million. More than three-fourths of all persons reporting disabilities were not in the labor force (see Exhibit 1). Moreover, more than one-fourth of all people not in the labor force (i.e., neither employed nor seeking employment) report a work disability. While one does not expect equal representation of disabled people within the employed and not-employed categories, given that disabilities can prevent one from working, the contrast between the two groups is stark: 4.8% of all employed persons reported a work disability, as compared to 26.8% of all persons not in the labor force.

Only one-third of all youth with disabilities graduate to a job or some form of advanced education. In most school systems in this country, youth with disabilities are not guided into employment opportunities appropriate to their abilities. Although varied degrees of vocational training

EXHIBIT 1

Number of Persons with Limiting Work Disabilities By Labor Force Status -- 1980

LABOR FORCE CATEGORY	NUMBER (IN MILLIONS)	PERCENT OF TOTAL DISABLED	PERCENT OF TOTAL POPULATION IN SAME CATEGORY
Employed	4.6	20.4	4.8
Unemployed	0.6	2.7	8.7
Armed Forces	0.1	0.2	3.3
Not in Labor Force	17.4	76.7	26.8
TOTAL	22.7	100.0	

Source: 1980 Census, Public-Use Microdata Sample (0.1 percent sample).

and education experiences are made available to many students with disabilities, a systematically planned transition to positions in the public and private sectors is not usually available. The absence of systematic vocational transition services often accounts for the continued high unemployment rate of persons with disabilities.

Vachon (1985) used data from the Social Security Administration's 1978 Survey of Disability and Work as a basis for estimating the incidence of disability in the year 2000. His forecasts project (p. 3):

- A 30% increase in the total number of work disabled individuals by the year 2000.
- A modest decline (-2.4%) in the numbers of young persons with work handicaps (ages 18-34).
- Dramatic increases (58.9%) in the number of work-disabled persons between the ages of 35 and 54.

These forecasts were used to predict changes between 1978 and 2000 in the labor force status of work disabled persons. Vachon's results indicate:

- Relatively constant rates of unemployment and labor force nonparticipation.
- A 21% increase in the actual number unemployed.
- An 11% increase in the number not in the labor force.

What factors are responsible for this projected growth in the work disabled population in the United States? The primary underlying force is the "aging" of the "baby boom" generation, i.e., persons born between 1946 and 1964. During this period, the birth rate increased significantly, then decreased, thus creating a generation of people who will mature together. This trend is demonstrated by increases in the median age. In 1985, the median age was 31.2; by the year 2000 the median age is projected to be 36.3 years. In the year 2000, most work disabled persons will be between the ages of 35 to 54 years.

Paid employment is the best and most dignified way for disabled people to obtain an adequate income. Income maintenance programs do not encourage the person toward their potential. When a person is employed, there is the potential for advancement or getting another position. This paper discusses existing employment programs and initiatives. Recommendations are presented that are directed toward increasing employment opportunities for disabled Americans.

II. TRANSITION

The Office of Special Education and Rehabilitative Services (OSERS) in the Department of Education has developed a transition model which is a bridge between the security of school and the risks and opportunities of adulthood. It is based on sound preparation in high school, adequate support mechanisms upon leaving school, and secure opportunities and services, as needed, in adulthood. It is an outcome-oriented process which encompasses a broad range of experiences and services which result in competitive employment. This process includes high school, graduation, additional post-secondary education, adult services, and the beginning years of employment. Emphasis is on a shared responsibility of all involved parties and extends beyond service coordination to examine the appropriateness and quality of the services provided (Will, 1984).

The successful transition bridge from school to employment is built on two foundations. First, there must be a solid educational foundation. This means that special education, vocational education, and other school based services collaboratively provide the skills, attitudes, personal relationships, and employer contacts that are essential for students to achieve successful transition. The curriculum must help students to develop saleable, entry level job skills. Instructional procedures must be designed so that curriculum goals are achieved by the full range of persons with disabilities. Guidance counselors, vocational educators, special educators, and vocational rehabilitation counselors must ensure that the Individualized Education Program process guarantees sound transition outcomes. Disabled students must be integrated into nonspecial education settings so that nondisabled peers and adults will have positive perceptions about disabled persons' abilities. Concomitantly, disabled students will develop age appropriate social behaviors reinforced in integrated settings. The student and his or her family are the driving forces of this process.

The second foundation of successful transition is adequate community-based employment opportunities. Even the most outstanding educational program is incomplete if appropriate competitive employment options are not available in communities. Neighborhood and family networks, the degree of the person's integration into community activities, and intense job search efforts all increase the probability of achieving employment.

At the same time, negative factors that affect the overall employment picture for disabled persons must be considered, including periods of low economic growth, job discrimination, as well as other conditions that result in unemployment for youth, unskilled workers, and other disadvantaged groups. Therefore, issues such as minimum wage levels, incentives to businesses to offer employment, equal employment opportunities, and structural unemployment problems must be addressed along with transition from school to work issues. Without this simultaneous attention, the dream of social and economic independence will not be realized by the vast majority of young people with disabilities (Will, 1984).

Thus, competitive employment is the chief goal of the OSERS Model. It is an objective measure of success of an effective transition program. The Association for Persons with Severe Handicaps stated in 1983 that the quality of employment for persons who are disabled should be defined and assessed the same way it is for nondisabled persons:

> The quality of employment and related day and vocational services for individuals with...disabilities should be judged by the same criteria used to evaluate the employment of others in our society; income level and the resulting opportunities created by that income; quality of working life, including integration of the work place, safety, and access to challenging work; and security benefits, including job mobility, advancement opportunities, and protection from lifestyle disruptions due to illness or accident (Will, 1984).

Full, sustained, competitive employment is possible for most persons, despite the nature and the severity of the person's disability.

However, five major obstacles to employment affect students leaving secondary special education programs. These are:

1. Scarce competitive employment opportunities
2. A maze of service providers and funding agencies
3. Eligibility requirements which differ from agency to agency.
4. Service providers who do not fully grasp the complexity of the systems
5. Consumers and families who are confused by the various service complexities.

Therefore, a coordinated, well-planned collaborative transition process to employment is needed for students who are in secondary special education programs. This process needs to begin in late elementary school and develop in a systematic way, with vocational education, special education, and vocational rehabilitation working together so that by the time the student leaves secondary school, he or she will have the skills and capacity needed for the transition to post-secondary educational programs and/or competitive employment.

For transition to be successful, a variety of community based, competitive employment opportunities must exist. Labor issues and overall economic issues must be addressed for transition to be successful, and economic incentives must be developed so that employers will hire disabled persons. The family, community integration, and neighborhood networks are also key factors in a successful transition process.

A. OSERS Model Transition Programs

To help special education students become employed, OSERS supports two different levels of transitional services that respond to the special needs of individual students. The first program is transition from school to work with very few special services. Many disabled individuals are able to rely on their own resources to obtain employment. Some special accommodations may be necessary, but they are usually found outside the realm of disability related services. Often persons find their own jobs through work experience programs, family networks, or short-term volunteer jobs. Others move on to post-secondary education programs to increase their skills and improve their employability. Often vocational and technical schools, community colleges, and other schools of higher education play important roles in the transition process for students with special needs. The exact number of students in this category at any one time is unknown, but the number varies with job availability, quality of education, and access to community services.

The second program is transition with time limited services. These temporary supports include vocational rehabilitation, post-secondary vocational education, and other job training programs which help gain entry into the employment market. To participate in these time limited programs, a person must be considered capable of continuing on his or her own after the services terminate. In other words, there is a reasonable expectation of employment at the end of a given period of time. This does not always result in competitive employment for the person who is disabled.

B. Legislative and Program History

Three major pieces of legislation directly affect the transition from secondary school to competitive employment of disabled students:

1. The Education of All Handicapped Children Act - Public Law 94-142, as amended by P.L. 98-199
2. The Vocational Education Act - Public Law 88-210, as amended by P.L. 98-524
3. The Rehabilitation Act - Public Law 95-602, as amended by P.L. 98-221

Each Act and its relationship to the transition process is discussed in detail below.

1. Education of All Handicapped Children Act - Public Law 94-142 (P.L. 98-199, Transition Amendment). In an effort to encourage states to upgrade their transition programs, the Secondary Education and Transitional Services for Handicapped Youth Program, Section 626 of Part C, was added to Public Law 94-142 when it was amended in 1984. This new legislative program provides funds for projects that will strengthen and coordinate education, training, and related services to aid in the transition to competitive and supported employment, postsecondary training and education, and adult services. In addition, it includes projects that will stimulate the development and improvement of secondary special education programs.

Numbers Served. In its Seventh Annual Report to Congress, 1985, the Office of Special Education Programs states that services to secondary and postsecondary students have increased at a high rate over the past few years. Due to the recently emphasized goal of employment after special education, services to these older students have been receiving growing attention. Accurate data is not currently available, but the child counts from fifty States show that the number of eighteen to twenty-one year olds served in public schools has increased by over two-thirds in the past five years. In 1983-1984, 186,393 students were served in this age group.

Further, the Report States that between 1982-83 and 1983-84, 37 States showed increases in the number of students in the 18-21 age group for an 82% increase in 1983-84 over the number served in 1978-79. Eight States are finding that services to this age group are increasing at a faster rate than are services for younger children. In 1984, 28 States had mandates to serve handicapped youth through age 21 if they had not yet completed high school. (See following Chart.)

Number and Percentage of Handicapped Students Aged 18-21
Served under P.L. 94-142 from 1978-79 to 1983-84

Year	Number of Students Served	Percent
1978-79	102,173	0.60
1979-80	124,528	0.74
1980-81	139,565	0.82
1981-82	159,399	0.92
1982-83	173,642	1.02
1983-84	186,393	1.12

NOTE: Percentages are based on the resident population of this age group for each year.

Given this growing number of students, special education must provide students with the knowledge and skills that will enhance their employment chances and help then make a successful transition with increased economic and social independence.

Current Expenditures. During Fiscal Years 1984 and 1985, the Office of Special Education Programs allotted approximately $23 million dollars to the transition and supported work initiatives. This sum includes both secondary and postsecondary projects. The money was divided among four divisions of Special Education Programs, as follows:

Division of Educational Services	=	$13,600,000
Division of Personnel Preparation	=	3,800,000
Division of Assistance to States	=	500,000
Division of Innovation and Development	=	4,900,000
		$22,800,000

Exemplary Models. The $23 million that Special Education Programs allotted to transition have funded some excellent projects. For example, during the 1983-84 school year, the Delaware Department of Education initiated a project to develop a model for coordinated transition from secondary schools to the work world for students with handicapping conditions. Designed to coordinate planning and service delivery among the special education, vocational education and vocational rehabilitation service systems, this project focuses on the needs of students when they enter secondary school, at about the age of 15. The project is jointly funded by the State Education Agency, with funds available under the P.L. 89-313 Program, and the Division of Vocational Rehabilitation of the Department of Labor. Vocational rehabilitation services personnel work with special educators early in the students' secondary school career to identify needs and plan prevocational and vocational training services consistent with those needs. In addition to providing more effective vocational preparation to individual students, this project will identify overlaps and gaps in available services among agencies and to determine how programs can be coordinated and integrated to best meet the needs of handicapped students. During the 1984-85 school year, the project operated in five sites, including special schools for the handicapped and regular high schools.

Also, in Winchester, Massachusetts, a new program provides an extra year of high school for special education students who plan to go on to college. The program will be based on Individualized Education Programs (IEP's) for each student but will focus on developing the study and social skills needed for college. Counseling and guidance concerning the entrance requirements of specific colleges will be provided, as well as follow-along services to ensure that the transition to college is successful. Evaluations of these projects will provide information about how to provide effective transition services and guidance for replication by other agencies and adult services providers.

For mildly and moderately handicapped students, transition often requires some type of time limited post-school services that will enable students to move on to employment. Interagency agreements between special education, vocational education, vocational rehabilitation, and developmental disability agencies have been a recent trend. Often State agencies negotiate these agreements and implementation procedures are developed at the local level. An Oklahoma project provides an example of how the process works.

In the State of Oklahoma, the Cooperative School/Rehabilitation Work Program is a major cooperative effort between Special Education and Vocational Rehabilitation. The State level interagency agreement specifies that special education will provide career awareness, job skill training and work-study activities. Vocational education counselors are part of the IEP team if vocational education goals are involved; vocational rehabilitation counselors serve on the IEP team if rehabilitation services are recommended; and collaborative IEP/IWRPs (Individual Written Rehabilitation Plans) are often developed. Students eligible for both special education and vocational rehabilitation attend special education classes for part of the day and vocational training, on-the-job training, or paid community work experience for the remainder of the day. Special education teachers and vocational rehabilitation counselors work as a team to provide these services. In school year 1983-84, approximately 2,000 students were served in this manner throughout the State of Oklahoma (OSEP Report to Congress, 1985).

One of the ultimate goals of all education, regular and special, is the development of skills needed for employment. The new section of the Education for All Handicapped Children Act that encourages States to develop and/or improve a coordinated transition process will help ensure that disabled youth attain and maintain employment.

2. Vocational Education Act - P.L. 98-524. Students with disabilities should benefit greatly from the Carl Perkins Vocational Education Act of 1984 that went into effect July 1, 1985. The following provisions described below relate to education, transition, interagency cooperation, and ultimately to competitive employment for students with special needs.

Vocational Education Programs. The purpose of the legislation is to help States expand, develop, and/or improve the quality of vocational education programs in order to develop marketable skills in the work force and to improve the country's economic growth. Furthermore, specific groups of students who may have been inadequately served by vocational education programs are assured access to these programs under the new law. These groups of students include those who are disadvantaged, handicapped, entering nontraditional occupations, adults who are in need of training and retraining, and/or individuals who may be in correctional institutions (Whitehead & Rhodes, 1985).

The vocational education programs may be delivered in a variety of both public and private settings, including high schools, sheltered workshops, trade schools, and adult education programs. Handicapped persons are defined as persons who cannot succeed in regular vocational education programs without special education assistance.

State Councils and Plans. A second provision requires that each State have a Council to advise the State Board of Vocational Education on the development of its State's plan. It also advises the governor, business persons, and the public about policies that the State should adopt to strengthen vocational education with particular focus on populations that are handicapped. In addition, each State plan has a requirement that it assess the needs of special groups for access to vocational education and vocational services in regard to the labor market needs. Handicapped persons are the first special group mentioned. The State plans must describe how the provisions pertaining to disabled students will be enforced. They also must describe the measures that will be used to evaluate the effectiveness of the programs. Furthermore, the plans must describe the joint efforts under the Job Training Partnership Act, the Education of All Handicapped Children Act, and the Rehabilitation Act (Whitehead & Rhodes, 1985).

Ten percent of each State's basic grant must be set aside for supplemental staff, equipment, materials, and services that are essential in order for handicapped individuals to take part in vocational education. The new legislation prohibits States from using the 10% set aside money to pay the full costs of segregated vocational education programs. The State must match the Federal 10% set aside funds, and the combined monies can only be used to pay the excess costs that result from providing vocational education to disabled students. Eligible recipients are to receive 100% of the State set aside funds.

Assurances for Disabled Students. A third major provision of the Act lays out the following guidelines for serving disabled students:

1. Equal access will be provided to disabled persons in recruitment, enrollment, and placement activities.
2. Equal access will be provided to all handicapped students for the full range of activities available to all other persons. This includes apprenticeship programs, cooperative education, and courses pertaining to specific occupations.
3. All programs will be provided in the least restrictive environment and will, when appropriate, be included in student's individualized education plan (IEP).
4. At least one year prior to a student's entering the grade at which vocational education usually beings, or by the start of the ninth grade at the latest, each local education agency shall give disabled students and their parents information regarding the availability of vocational education opportunities and the eligibility criteria for enrolling in the program.

After a disabled student has enrolled in a vocational education program, he or she shall receive:

1. An assessment to determine interests, abilities, and special needs to successfully complete the program.
2. Special services, including equipment, adapted curriculum, instruction, and facilities that are designed to meet the special needs identified in the assessments.

3. Guidance, counseling and career development activities from counselors who usually provide these services.

4. Counseling services that will facilitate the transition from school to career. These services include job development, placement and follow-up procedures.

These provisions and assurances should increase vocational education opportunities for students with special needs.

Numbers Served. According to the Seventh Annual Report to Congress in 1985, the Office of Special Education Programs reported that approximately 290,000 disabled students were enrolled in vocational education programs during 1981-82. The data indicated that 64.2% of these enrollments were in regular vocational education programs with no special services. If those disabled students who required special services are included, the aggregate enrollment rises to 490,000. The Office of Vocational and Adult Education reports that 74.7% of the handicapped students served are in regular vocational education programs.

With the requirements in the new Vocational Education Act, there should be significant changes in the number of students served and the ways in which they are served. School districts will move from special vocational classes to regular vocational classes with a variety of support services for the students with special needs (Cobb & Kingsbury, 1985).

Current Expenditures. Congress authorized a funding level of $950 million; however, the appropriation for Fiscal Year 1985 was $835,300,000. Each year Congress will determine how much money to authorize for each Title of the Act.

Exemplary Models. The new Act encourages vocational educators to make contacts with community-based organizations that provide training and employment. Some States have initiated interagency agreements among State and local service providers in an attempt to build up the coordination of services to populations with special needs. According to Cobb and Kingsbury, Wilmar, Minnesota is an excellent example. Six agencies--three community-based organizations, the Department of Vocational Rehabilitation and the Education Department's Offices of Vocational Education and Special Education--signed a joint agreement designed to coordinate planning, case management and follow-up of handicapped individuals, from the age of 16 until after graduation. Major provisions included the purposes of the agreement; the eligibility criteria (who can receive services); the referral process of clients and agencies; assessment services available (and who could provide them); the case management responsibilities of the respective agencies; the fiscal responsibilities of the agencies and clients; and the duration of the agreement and evaluation provisions. This future-oriented collaboration shows what promise vocational education can hold for students with special needs. Both the quality and quantity of services should increase under the Perkins Vocational Education Act.

3. Rehabilitation Act of 1973 as Amended by P.L. 98-221. Title II of the Act established the National Institute of Handicapped Research (NIHR) and authorizes project grants for research, demonstration and related activities designed to develop methods, procedures and devices to assist in providing vocational rehabilitation services to handicapped individuals, especially those with the most severe handicaps. Such projects may include: (1) studies and analyses of industrial, vocational, social, psychiatric, psychological, economic, and other factors affecting rehabilitation of handicapped individuals; (2) special problems of homebound and institutionalized individuals; (3) studies, analyses and demonstrations of architectural and engineering designs adapted to meet the special needs of handicapped

individuals; and (4) related activities which hold promise of increasing knowledge and improving methods of rehabilitation of handicapped individuals, including those with the most severe handicaps.

The National Institute of Handicapped Research has awarded approximately $1,471,500 in contracts, grants, and fellowship awards for research pertaining to transition and supported work. This figure includes expenditures for Fiscal Years 1984 and 1985.

Several NIHR projects offer effective transition opportunities to youth who are disabled. These projects creatively use interdisciplinary staff members to meet the special needs of the students/clients. NIHR also is funding a research and training center at Virginia Commonwealth University, Richmond, Virginia, that focuses on improving the employability of mentally retarded individuals. It specializes in providing high-quality research and training in the area of competitive employment. Job-placement, job site training, and follow-up services are part of the scope of work, and center staff work with employers, parents, secondary education programs, sheltered workshops and adult programs as part of the transition component.

Other efforts include training and providing technical assistance to vocational rehabilitation personnel to help develop and/or expand transition services. Through the combined effort of Special Education Programs and the Rehabilitative Services Administration (RSA), leadership conferences on transition programs have been held in each RSA region. Each Regional Office has assisted in the development of at least one new transition project in each State. Also, each Region is identifying existing cooperative agreements and working to improve the effectiveness of those agreements.

4. The Job Training Partnership Act (JTPA). The Job Training Partnership Act (JTPA) of 1982, P.L. 97-300, authorizes job preparation and job training for people who are economically disadvantaged and for people who face serious barriers to employment. Emphasis is placed on the achievement of goals to increase the employment of participants and to reduce dependency.

JTPA funds go from the Federal government to the Governors of each State. Each Governor appoints a State Job Training Coordinating Council to propose designated Service Delivery Areas (SDA) for the dispersal of all funds, including discretionary funds. The chief locally elected officials in each SDA consider nominations from various agencies in the SDA and then appoint a Private Industry Council (PIC) to develop a job training plan for spending the JTPA funds. The Law and the regulations governing the dispersal of funds allow localities enough discretion to channel funds toward serving individuals with developmental disabilities. The regulations governing JTPA performance standards also allow some discretion within the definitions applying to "positive terminations." The fact that a client can be designated as a positive termination if he/she has achieved PIC (locally) recognized competencies gives the PIC the ability to serve more individuals with severe handicaps because they can be included as positive terminations.

Unlike the earlier Comprehensive Employment Training Act (CETA) program, JTPA does not consider a person eligible simply because their handicap is considered a substantial barrier to employment. Under JTPA, individuals with handicaps are required to meet income eligibility criteria in order to qualify for services. This factor has limited the participation of individuals in the program, eventhough this eligibility requirement may be waived in some instances.

JTPA has given the business community considerable responsibility in designing and operating the program. A majority of the membership and the chairperson of each SDA's Private Industry Council (PIC) must represent business and industry. Rehabilitation agencies and community-based organizations must also participate on the PICs and State Job Training Coordinating Councils.

Since this program is relatively new and has very unstructured Federal guidelines regarding target populations, it is extremely difficult to assess its actual impact on disabled youth. In Fiscal Year 1984, Congress appropriated $2 billion for the program. From this money, the Association for Retarded Citizens received $1,680,000 to recruit, train, and place mild to moderately retarded clients. The Epilepsy Foundation also received a $695,000 training contract for the same year (Rehabilitation Information Utilization Institute, 1985). Anecdotal reports from disabled people suggest, however, that persons with disabilities are not being well served by JTPA.

5. Targeted Jobs Tax Credit Program (TJTC). This legislation affords employers the opportunity to take Federal income tax credits when they employ persons from specifically targeted populations. The procedure is not complex, and employers have no training requirements to meet, no reporting requirements, and a minimum amount of paperwork. They retain absolute authority in hiring. The TJTC program was extended and revised in The Tax Reform Act of 1984 and merged with other programs as a new "general business credit" program. Some States, including California, have enacted State laws which provide for a State TJTC program (i.e., credits on state income tax for employers).

A key factor for a successful transition is the involvement of employers. This legislation provides an incentive to employers who may be reluctant to hire persons with disabilities. (A detailed description of TJTC program is included under the Placement Initiatives section below.)

6. Section 1619(a) and (b) of the Social Security Disability Amendments. This legislation affects the employment eligibility of Supplemental Security Income recipients. The purpose of Section 1619(a) is to protect and continue the SSI benefits portion of the total income of the disabled recipient whose work earnings would normally cancel out basic SSI benefits, even though he or she remains severely impaired. Without this protection, a recipient would lose benefits the month after the second month of earning at the Substantial Gainful Activity (SGA) level. Instead, 1619(a) continues the SSI benefits as an incentive for the recipient to continue working. Benefits are paid on the basis of a formula until earnings reach $713 per month for an eligible individual and $1,029 per month for an eligible couple (1984 levels). At that point, all SSI benefits cease.

Section 1619(b) assures that working SSI recipients continue to have Medicaid coverage if (1) their disabling condition continues; (2) they would have difficulty maintaining their employment without medical coverage; and (3) their earnings are not high enough to obtain benefits equivalent to the SSI benefits (including the State supplement) and the Medicaid benefits that they would have received had they not accepted employment. Section 1619(a) and (b) is discussed further in the paper, "Disincentives to Work under the Social Security Act," appearing later in this volume.

In summary, the legislation that mandates special education, vocational education, vocational rehabilitation, and the other programs that affect the economic future of disabled youth has an over-riding goal. That goal is to provide disabled young people with the training, skills, and competencies they need to attain and maintain employment and varying degrees of independence in their own communities. These programs respond to the adage, "Give a man a fish and you have fed him for a day. Teach a man to fish and he can feed himself a lifetime."

C. Gaps in Programs and Legislation

A well-planned and coordinated transition program should have the following elements:

1. Education should be provided in integrated settings.
2. Sequential career education curricula that result in employment should be developed and established for special education students at an early age.
3. Vocational education, special education, regular education, and vocational rehabilitation personnel should cooperatively develop career goals and objectives for students.
4. Students and families should be involved in all decisions
5. Employers should be involved in the transition process to ensure the availability of appropriate community-based worksites and employment opportunities.

Unfortunately, many students leave high school special education programs without having been part of a coordinated transition process. There are several reasons for this omission:

1. Lack of Ownership. The first reason is a lack of ownership of the transition process among educational and rehabilitation agencies. Transitional plans may begin with the school, the rehabilitation agency, or the family. The age at which this transition process should begin varies

from district to district. However, it must begin long before it is time for the student to leave special education.

In addition, special education, vocational education, and vocational rehabilitation program administrators may not recognize the need for their Federal, State, and local counterparts to communicate between and among themselves. They also may not provide interdisciplinary in-service training for special educators, regular educators, vocational educators, and vocational rehabilitation counselors so that these professionals can coordinate their programs for disabled students.

Furthermore, these program administrators may not recognize the need for students to receive interdisciplinary training experiences; nor do they always recognize the need for including such experiences in a student's Individualized Educational Plan (IEP).

2. Lack of Program Coordination. A second reason for the lack of a well-planned transition process centers on the lack of coordination within and among special education, vocational education, and vocational rehabilitation programs across the country. Vocational goals may not always be included in students' IEPs, and vocational rehabilitation personnel may not be involved in the IEP process. A great many inconsistencies exist among school districts for developing and writing IEPs. Therefore, many IEPs lack foresight and employment-oriented goals.

Students and families may not be included in or informed about vocational education and rehabilitation options both in school and after graduating. Thus, many disabled students are denied involvement in and exposure to career possibilities that are appropriate for their individual needs.

Additionally, skills taught may not reflect future employment and career trends and opportunities. Students may be learning job skills that are confined to today's job market and not to the job market that will exist upon graduation. Vocational assessments may not be comprehensive, further complicating the type of job skills being learned. Career counselors are usually few and far between, and special educators may rarely venture into the private and public employment sectors in order to further develop their students' career goals and options.

Finally, special education programs usually do not include independent living skills that are comprehensive and apply to and are essential for job attainment and maintenance. This includes learning how to manage activities of daily living, such as household routines, finances, transportation, recreation, age appropriate social behaviors, and, for some, personal care attendants. Without these skills, economic and social independence may not be realized.

Gaps exist in the transition process because vocational education programs may not fully involve all special education students. In particular, students who are severely disabled are excluded. In addition, vocational educators usually are not trained in special education techniques. These teachers may lack the knowledge needed to analyze and modify tasks, and may not be familiar with the availability of special resources and adaptive equipment. Also, vocational education goals and personnel may not be included in the IEP process. Lastly, students and families may not even be aware of the availability of vocational education services.

Many students have an unsuccessful transition process because vocational rehabilitation counselors may not be involved in the IEP process.

Also, IEPs and Individualized Written Rehabilitation Plans (IWRPs) may have goals and objectives that are incongruent. Severely disabled students are often excluded from vocational rehabilitation programs. When vocational assessments are performed, the results may not be communicated to special educators and others involved with the students. Vocational rehabilitation counselors may be unfamiliar with task analysis, worksite modifications, special education techniques, the availability of adaptive equipment, and/or other community-based resources.

3. Omission of Other Service Agencies. Transitional programs are often poorly planned because other service and educational agencies are omitted from the process. Too often, mental health agencies, developmental disabilities councils, social service agencies, and independent living centers are not members of the transitional planning team. Also, community colleges, technical schools and universities are overlooked as viable transitional options for large numbers of students with special needs.

4. Omission of Employers. All too often employers and civic agencies may not be considered and involved in the transition process. Without a corps of aware and interested employers, there will not be a sufficient number of on-the-job training and supported and non-supported community-based employment options available to students who are leaving secondary special education programs. The outcome objective of job skills and vocational training is ultimately employment. Without jobs, job training is nonproductive, and may, in fact, discourage disabled youth from ever seeking employment (Nelson, Fischer, & Rubenstein, 1985).

5. Legislative Gaps. Most Federal laws that mandate special education and vocational rehabilitation services lack mechanisms for making one of

those program areas responsible for taking the lead in transitional planning. Each local and State program usually waits for the other to initiate the transitional planning process. Often valuable time is lost, and students and society pay the price because a specific agency is not designated to start, coordinate, and follow-through the transition process from high school to employment.

Both Public Law 94-142, as amended, and the Rehabilitation Act are incomplete because they lack the mechanisms needed to ensure that cooperative, interagency efforts will be in place to start and carry-out the transition planning, training, and employment processes. Without this prescribed role, students will always run the risk of an inadequate transitional program. In addition, education is an entitlement program; employment services are not, and eligibility varies with the discretion of the case managers and counselors. Federal guidelines are broad. States may establish eligibility policies and standards that are narrow and unflexible. Counselors may exercise degrees of selectivity in choosing and servicing clients (Whitehead & Rhodes, 1985). This leaves many persons either under served or not served at all.

Other legislation affects the ultimate transition goal of providing integrated employment opportunities for persons with special needs. Although the Job Training Partnership Act legislation should help to increase the employment and decrease the dependency of disabled persons, it has shortcomings. Despite the fact that State governors have the authority to adjust the national standards in the law, few have acted favorably on this authority. The result is that few persons with severe disabilities take part in Private Industry Council-sponsored programs (Whitehead & Rhodes, 1985).

Unlike its predecessor, the Comprehensive Employment and Training Act (CETA), JTPA does not consider a person eligible because his/her handicap might be a barrier to employment. Income eligibility criteria must be satisfied in order to receive services. If a disabled person is considered a family of one, the income standard may be waived, even if his or her family's income exceeds the limit (Whitehead & Rhodes, 1985).

In addition, the public lacks awareness about the programs under the law. Even those who do know about it find it difficult to understand, and many require a strong advocate to utilize it.

Lastly, according to Whitehead and Rhodes:

> In evaluating the impact of JTPA, the President's Committee on Employment of the Handicapped and a project at the University of Wisconsin have found evidence that participation of individuals with disabilities in JTPA has been quite restricted. This may be due in part to the fact that PICs are not required to detail the procedures necessary to meet the employment needs of persons with handicaps. On the other hand, PICs are required to establish performance standards which become the criteria used in program evaluation. The standards are often rigid, failing to recognize the unique needs of individuals with handicaps. This can lead to a "creaming effect" in the selection of participants.

Section 1619(a) and (b) of the Social Security Disability Amendments of the Social Security Act has been underutilized by persons who could benefit from it. Often Social Security personnel are not fully informed about the section. Thus, clients remain unaware of it and how to access it (Whitehead & Rhodes, 1985). Despite the fact that this legislation has been extended until June 1987, there is no guarantee that it will be made permanent. Even in its current form, disabled persons may obtain employment at a salary level that is too high for Medicaid coverage, even though they cannot obtain adequate health benefits from their employers (Elder, 1985). This disincentive to competitive employment is discussed in the "Disincentives" paper in this volume.

In summary, many students with special needs are leaving high school special education programs without participating in a well planned, coordinated transitional program. There are several reasons why this is occurring:

1. No agency is mandated to start and carry-out the transition process
2. Programs serving adolescents lack coordination within and among themselves
3. Employers and civic agencies are not encouraged to take part in the process to ensure the availability of jobs in the community
4. Existing legislation has shortcomings that impede the transition process and ultimate employment.

III. SUPPORTED WORK

> "I expect my ten year old daughter who is in a TMR class to have viable job skills when she gets out of school. In fact, by the time she is 21, I expect her to have a job that pays a decent wage so that she can live independently, perhaps in a group home or supervised apartment program. I'm making sure that vocational training is included in her IEP, that the schools are doing real job training, and that by the time she's in high school, the school works with our community service board and a rehabilitation couselor to get her into the right kind of job." (Wehman, et al., 1984)

Unfortunately, this expectation is not realized for 50-80% of all adults with disabilities. Between 250,000 and 300,000 students graduate from special education classes yearly. Despite the fact that our nation invests over $1.5 billion annually in special education, and 8% of the gross national product is spent on disability programs, the promise of employment and community integration is not a reality for one-third of the disabled young people leaving special education (Will, 1984).

These graduates usually enter publicly-supported day activity and vocational centers where they face segregation from non-disabled peers, slow movement towards employment, and low wages. In order to rectify this inequitable situation for so many physically and developmentally disabled young Americans, an orderly, systematic transition process to employment and community integration is needed. The special education investment demands that full participation in community life be achieved through coordinated, interagency, transitional planning. This planning is a five-step process that includes:

1. Relevant, age-appropriate school instructional programs that will lead to employment.
2. Formal organized planning for the movement from school to competitive employment.

3. Creation of multiple meaningful, competitive, community-based employment options.
4. Parental involvement and consent in decision-making.
5. Cooperative focusing by educators, service providers, and employers on improving the quantity and quality of competitive employment opportunities in communities with time-limited and ongoing support services as they are needed.

For persons with disabilities, the transition from school to competitive employment is complicated by society's stereotyped attitudes and is further hindered by the maze of services which are believed to provide assistance to adults but may in fact foster dependence.

A. Supported Work Program: OSERS Model

The supported work program approach is a fundamental change in current policy and practice. Supported work programs are designed to change how existing services are delivered. They are not designed to increase existing services or to change who receives the services (Bellamy & Melia, 1984).

At this time, the majority of adult services for persons with severe disabilities are nonvocational. These services usually involve life-long custodial care or prevocational options which offer little, if any, movement to meaningful rehabilitation and employment. These are merely alternatives to work that exclude persons from viable employment opportunities (Will, 1984).

Ongoing services, however, offer employment with whatever support is needed to maintain that employment. This support may be temporary or episodic, but the person needed for intervention is always available (Bellamy & Melia, 1984). This program allows local services and supportive policies to develop combinations of work opportunities for persons who are disabled to such a degreee that competitive employment at or above the minimum wage is likely. Supports are given through training, supervision, and/or transportation. It takes place in a variety of settings where able-bodied workers are also employed.

There are four components in the ongoing services model. The first takes place in light industry where a small group of disabled workers receive ongoing services from a work supervisor who is paid by the responsible State agency. The second involves scattered placements of disabled individuals in a community, with publicly-funded support staff rotating among work sites. The third component has a mobile crew of disabled persons who have a full-time publicly-funded supervisor. The fourth component involves a converted day activity program that operates a business that is successful enough to provide full-time employment opportunities to disabled participants.

Furthermore, extensive programs are being developed to prepare handicapped students of all severity levels for employment upon completion of high school. The extent, duration, and type of supportive services required vary, as do the agencies providing such services. Programs and interagency agreements to provide support services and vocational training are being developed. While some programs lead directly to employment upon graduation, others provide time-limited or long-term support to prepare for or support competitive employment. Some of these programs are described below:

- In Great Falls, Montana, a community-oriented work/study program provides services to mildly handicapped high school special education students who will probably not obtain further formal education. Intensive vocational training incorporates functional academic training that is focused on jobs which are currently available in the local community. It is provided in classrooms and at job sites in the community. On-going counseling and retraining are provided, as needed, after graduation from the program.

- An Oregon High School project developed a set of procedures which have been replicated in a number of communities for creating a work-related curriculum for severely handicapped students. The curriculum includes work skills, self-management techniques, and leisure activities. Using the natural routines of working and living as the mode of instruction, teaching takes place within the community setting. Both school staff and parents are directly involved in planning for the post-school placement of the student based on the student's skills and available opportunities in the community.

- A program which will result in supported employment for the students who are severely disabled is provided at Virginia Commonwealth University. The goal is to obtain competitive employment for students before they graduate from public school. This project is using a supported work approach which consists of four major components. Job placement requires the careful match of a real job to a specific student's skill level, employer capabilities, and parental concerns. Onsite job training and advocacy entails a trainer working onsite with the student, employer, and other employees until the student is competent in both the job and the social skills it demands. Ongoing assessment of student skills (performance) and adequacy of the job/student match occurs concurrently with the onsite training. Job retention is maintained by systematic follow-up responsibilities to post-school human services agencies.

B. Legislative and Program History

The pieces of legislation that directly affect the supported work programs are:

1. Rehabilitation Act of 1973, as amended by Public Law 98-221
2. Developmental Disabilities Act, Public Law 98-527.

A description of the legislation as it relates to supported work is discussed in detail below.

1. Rehabilitation Act of 1973, as Amended by Public Law 98-221. In Fiscal Year 1985, the Department of Education received a $3.7 million appropriation from Congress to carry out a supported work grant program under Section 311(a) (1) of the Rehabilitation Act of 1973, as amended.

This initiative is stimulate the development and provision of supported work for persons with severe disabilities on a statewide basis.

The Rehabilitation Services Administration reviewed applications submitted by States which were seeking to convert day activity programs into supported work programs. Awards were made October 1, 1985, to the successful State applicants who wanted to offer employment to individuals with disabilities severe enough to make them ineligible to receive traditional vocational rehabilitation services.

Thus, programs which come under the Rehabilitation Act of 1973, as amended, are beginning to develop supported work projects. These efforts must be publicized and replicated across the country in order to ensure that the disabled young people of America receive the appropriate education and vocational training and services which they require.

2. Developmental Disabilities Act, Public Law 98-527. The Developmental Disabilities Act of 1984 authorizes grant support for planning, coordinating and delivering specialized services to persons with developmental disabilities (DD).

The term "developmental disability," as defined in the Act, means:

> "a severe, chronic disability of a person which - (A) is attibutable to a mental or physical impairment or combination of mental and physical impairments; (B) is manifested before the person attains age 22; (C) is likely to continue indefinitely; (D) results in substantial functional limitations in three or more of the following areas of major life activity: (1) self-care, (2) receptive and expressive language, (3) learning, (4) mobility, (5) self-direction, (6) capacity for independent living, and (7) economic self-sufficiency; and (E) reflects the person's need for a combination and sequence of special, interdisciplinary services which are lifelong or extended duration and are individually planned and coordinated."

The 1984 Amendments of the Act added the provision of employment related services to the basic State Grant Programs as a priority area. The Act defines the term "employment related activities" as services that will increase the independence, productivity, or integration of persons with developmental disabilities in work settings. It includes such services as employment preparation and vocational training leading to supported employment, incentive programs for employers who hire persons with developmental disabilities, services to assist transition from special education to employment, and services to assist transition from sheltered work settings to supported employment settings to competitive employment.

The term "supported employment" means paid employment which (1) is for persons with developmental disabilities for whom competitive employment at or above the minimum wage is unlikely, and who, because of their disabilities, need intensive ongoing support to perform in a work setting; (2) is conducted in a variety of settings, particularly worksites in which persons with disabilities are employed; and (3) is supported by any activity needed to sustain paid work by persons with disabilities, including supervision, training, and transportation.

Part B: Federal Assistance for Planning Service Activities for Persons With Developmental Disabilities. Formula grants to States are authorized under Part B of the Act. To receive its Part B allotment, a State or Territory is required to establish a State Developmental Disabilities Planning Council. This Council, working in tandem with the designated State administering agency, is responsible for developing and submitting a State Plan which specifies existing gaps in services and identifies one or more priority service areas in which the State will focus its attention. By law, the

State Council must be composed of representatives of the State agencies primarily responsible for serving developmentally disabled persons and providers and consumers of such services.

States must select among the following priority service areas specified in the statute: (1) alternative community living arrangement services, (2) employment-related activities, (3) child development services, and (4) case management services. (Note: For any Fiscal Year after Fiscal Year 1986 for which the total appropriation under Section 130 is at least $50,250,000, employment-related activities must be included among the priority services to be provided under the plan.) In addition, under certain circumstances, a State may elect another priority service area, provided the area is specified in its State Plan. As defined in the law, service activities include: (1) specialized services which respond to unmet needs of persons with development disabilities; (2) model service programs; (3) activities to increase the capacity of agencies to provide services; (4) the coordination of priority services with other services; (5) outreach to individuals; (6) the training of personnel who provide services in the area, including parents of persons with developmental disabilities, professionals, and volunteers; and (7) similar services to expand the use and availability of services in the area.

The State Plan must provide that not less than 65% of the amount available to the State under its Part B allotment will be expended for service activities in the priority service areas. States may opt to make their second priority area one of their own designation, as long as the first is one of the four identified above.

Number Served. In order to find out how to best provide community services for developmentally disabled persons, the Administration of Developmental Disabilities requested that the Inspector General for Health and Human Services conduct a study. In April, 1984, the results of a Service Delivery Assessment on the Transition of Developmentally Disabled Young Adults from School to Adult Services were submitted to Jean Elder, Commissioner of the Administration on Developmental Disabilities. The study showed that 90,000 students with developmental disabilities were leaving special education each year (Elder, 1985). Approximately 6,000,000 persons or 3% of the population are now classified as having mental retardation, and these figures are rising (McCleod, 1985). Approximately one in ten Americans has a family member with mental retardation. Thus, there is a great need among this population for an organized, interdisciplinary planning process with a variety of employment training programs available in their communities.

Current Expenditures. The combined Federal and State expenditures for services to the developmentally disabled populations are approximately $14.3 billion. Of that total, the Federal Government spends $6.93 billion, and the States spend $7.40 billion. The Department of Health and Human Serivces spends $6.62 billion, or 95% of all DD costs (Regional Information Utilization Institute, 1985).

The Administration on Developmental Disabilities has allotted $500,000 specifically for the purpose of working with the Department of Education to implement a supported work initiative. This initiative includes $3.7 million from the Department of Education to encourage States to convert day activity centers into supported work programs.

Exemplary Models. The interagency agreement between the Administration on Developmental Disabilities and the Department of Education is one example of a supported work model. Since this legislation went into effect in October, 1984, the initiative with Education is just beginning, and there are few exemplary models to report. However, the Administration on Developmental Disabilities has surveyed 120,000 large and small businesses to determine their employment needs and whether they would like to know why it makes good sense to hire employees who are developmentally disabled.

Over 1,200 firms replied that they were interested. The information has been given to the State Developmental Disabilities Councils. Some groups set hiring targets: the National Restaurant Association set a target of 10,000 jobs in 1984 and 1985. The American Hospital Association pledged to hire 16,000 persons with developmental disabilities. The preliminary results of the data gathering show that at least 25,000 persons have been hired (Elder, 1985).

3. Targeted Jobs Tax Credit Program. Several supported work project employers participate in this program. In Montgomery County, Maryland, employers in printing shops, electrical fuse manufacturing plants, tee shirt silk screening shops, home/hardware stores, and other small industries hire persons who are severely disabled as a result of autism. These disabled persons are earning the minimum wage, living in small group homes, and learning to be as self-sufficient as possible. Without Targeted Jobs Tax Credits, these persons would be in day activity centers costing the taxpayers money rather than being taxpayers themselves.

4. Title XIX of the Social Security Act. This piece of legislation is the major Federal funding source for both institutional and community

care of persons with mental retardation. In Fiscal Year 1985, it accounted for 34.2% of the $7.7 billion which the Government spent on mentally retarded persons. By contrast, the Government spent 12% on noninstitutional Medicaid payments; 3.1% on special education; .25% on Title XX Social Services; and 1.7% on vocational rehabilitation (Conley & Noble, 1985).

Because such a large portion of funds go to institutional care, it is very difficult to develop the greatly needed community-based programs for disabled persons. In fact, the Health Care Financing Administration has put into effect regulations which are dissuading States from providing vocational and employment services. As a result, providing employment options under Title XIX opens a State to HCFA audits and the possibility of having to reimburse Federal Government for the funds spent (Conley & Noble, 1985).

5. Title XX of the Social Security Act. This portion of the Social Security Act provides funds for day activity centers and sheltered workshops, among other programs. According to the 1985 Regional Information Utilization Institute on Transition, "day activity programs have emerged in the last ten years as the primary community service approach for individuals with mental and physical disabilities so severe that they are ineligible for vocational rehabilitation. Day programs expanded by an estimated 600% between 1972 and 1979, in part due to State implementation of policies favoring community over institutional care. The California Department of Finance reported in 1979 that only 2.7% of the State's day program participants moved on to higher level vocational programs during the year. Data from New Jersey during 1980 provide a similarly low estimate of 3.5%.

Although generally believed to be fiscally and programmatically superior to institutions (the only current alternative service for many participants), day activity programs have come under increasing criticism for lack of movement to less costly and less dependent services, segregation from the mainstream, and lack of earnings by participants.

C. Gaps in Legislation

Supported work programs are an alternative to day activity centers. The nation's financial investment in special education programs for our disabled young people demands that upon leaving school they have more to look forward to than attending segregated centers. The dignity and worth of each person demands that he or she be a contributing part of society. Studies are showing that severely disabled persons are capable of performing productive work if given the support services needed. The Association for Retarded Citizens estimate that, with the appropriate training, 75% of children who are mentally retarded could be completely self-supporting as adults. Another 10-15% could be partially self-supporting if supported work programs were available (McCleod, 1985).

1. Public Law 94-142 and the Rehabilitation Act. Neither of these pieces of legislation contains a provision for funding the ongoing services needed by students entering supported work programs. Without this provision, the chances of these students being able to enter into competitive, community-based jobs are greatly reduced.

2. Title XIX of the Social Security Act. The Medicaid Amendments of 1981 were designed to relieve some of the funding crises facing community based services and their recipients. Due to unfortunate policy determina-

tions and legal interpretations, educational and vocational rehabilitation services have been excluded as eligible services. Although some States have developed waiver plans to allow funds for services related to employment, the outlook for long range, wide spread approval is dismal. In fact, most States have been advised to refrain from including any vocational and employment activities in their programs and plans (Whitehead & Rhodes, 1985). As long as States continue to rely heavily on Title XIX funds, employment related services will be at a minimum for disabled persons using those centers.

3. Title XX of the Social Security Act. Title XX was a major contributor to extended employment related services until 1978. At that time, funds to activity centers and workshops were greatly reduced, and States responded by cutting back the employment services. In 1981, the Social Security Block Grant Program Title XX authority specifically provided for vocational rehabilitation services (Whitehead & Rhodes, 1985). However, these services are in segregated facilities, with low wages and little chance for upward movement and interaction with nondisabled peers.

IV. PLACEMENT INITIATIVES

The legislation and programs described below directly affect persons with disabilities. In addition, the legislation listed below (described in the Transition and Supported Work sections) are important in meeting the education and training needs of persons with disabilities:

- Education for all Handicapped Children Act (Public Law 94-142)
- Carl D. Perkins Vocational Act of 1984
- Developmental Disabilities Act of 1984 (Public Law 98-527)

In order to enter or reenter the labor market, persons with disabilities must be adequately prepared by having the necessary knowledge and skills. The placement initiatives described below help meet this need.

A. Rehabilitation Act of 1973 (As Amended by Public Law 98-221)

The Rehabilitation Act of 1973, as amended, is an extremely complex piece of legislation. It is comprehensive and sweeping in that it tackles a multiplicity of the real problems handicapped individuals encounter (Pati, Adkins, & Morrison, 1981). The Act, as amended, authorizes a billion dollars in Federal support for training and placing mentally and physically handicapped persons into remunerative employment. To assist in accomplishing this goal, a wide variety of service, demonstration, training and research grant programs were established under the Act, including a major Federal-State grant-in-aid program.

The origin of the Federal-State vocational rehabilitation program can be traced back to 1920 when Congress enacted the first civilian program for assisting disabled persons to regain work skills. Since that time, the Act has been gradually expanded to include services to persons with a wide array of handicapping conditions and, in recent years, to focus increased attention on the needs of severely disabled individuals.

The Act defines the term "handicapped individual" to mean: "any individual who: 1) has a physical or mental disability which for such individual constitutes or results in a substantive handicap to employment; and 2) can reasonably be expected to benefit in terms of employability from vocational rehabilitation services provided pursuant to Titles I and III of this Act."

The Act also defines the term "severe handicap" to mean: "a disability which requires multiple services over an extended period of time and results from amputation, blindness, cancer, cerebral palsy, cystic fibrosis, deafness, heart disease, hemiplegia, mental retardation, mental illness, multiple sclerosis, muscular dystrophy, neurological disorders (including stroke and epilepsy), paraplegia, quadriplegia and other spinal cord conditions, renal failure, respiratory or pulmonary dysfunction, and any disability specified... in the regulations."

1. State Vocational Rehabilitation Agencies. Title I of the Rehabilitation Act authorizes formula grants to designated vocational rehabilitation agencies to provide basic rehabilitation services to persons with disabilities.

The Federal/State programs (the vocational rehabilitation agencies (VR)) provide services designed to help persons with disabilities obtain gainful employment. A wide array of services are provided:

- diagnosis and evaluation of rehabilitation potential and related services;

- counseling, guidance, referral and placement services, including follow-up and follow-along and post-employment services;

- vocational and other training services, including personal and vocational adjustment services, books and other training materials and family adjustment services;

- physical and mental restoration services, including corrective surgery or therapeutic treatment and related hospitalization, prosthetic and orthotic devices, eye glasses, special services, and diagnosis and treatment for mental and emotional disorders;

- income maintenance for subsistence during the rehabilitation period;

- interpreter and reader services, rehabilitation teaching services, orientation and mobility services for the blind; and

- transportation to rehabilitation services, and occupational licenses, tools, equipment, and initial stocks and supplies.

For the most part, rehabilitation services are similiar from one State to another. The standards of operation are uniform for all State agencies since they are established by the Federal regulations written by the Rehabilitation Services Administration. There may be some differences among States and regions, depending upon local needs, order of selection and interpretation of policy.

The vocational rehabilitation counselor is the key person within the State agency. The vocational rehabilitation counselor determines eligibility based upon the criteria set forth in the Rehabilitation Act; develops jointly with the client an Individualized Written Rehabilitation Program which outlines the vocational goal, objectives, services, funding source, and counselor's and client's responsibilities; and has the overall responsibility for job placement.

Placement is a service as well as a program outcome of the State agency. The success of the VR agency is measured by the number of Closed Rehabilitation Cases - Status 26. Placement is defined as "a process that expands and improves vocational opportunities and outcomes for disabled individuals." Placement is not simply finding employment for vocationally handicapped individuals; it is a process of matching opportunities appropriately with the client and ensuring that the person functions effectively at the level defined by the employer (CSAVR, 1985). The VR counselor provides services to the client along a continuum called the vocational rehabilitation process, that will ultimately led to a successfully rehabilitated client (Status 26). State/Federal programs agree that without placement, vocational rehabilitation does not exist; therefore, it benefits them to develop strong placement components within their programs.

In Fiscal Year 1985, Congress authorized $1.1 million for State vocational rehabilitation agencies.

Many studies have been made of the cost-effectiveness of the rehabilitation program. Results have ranged from as high as $35 to $1, to as low as $3 to $1. The cost benefit figures most widely accepted by VR agencies are that for every dollar spent, $10.00 are returned, plus the reduction in dependency on other Federal programs such as SSI, SSDI and AFDC.

In 1984, according to the RSA Caseload Statistics Report, State rehabilitation agencies served 936,180 persons. Of this number, 565,425 were classified as severely disabled, accounting for 60.4% of all persons served in Fiscal Year 1984. State agencies successfully rehabilitated 225,772 persons; of this number, 132,665 were severely disabled.

A break-down of the categories of employment was not available for Fiscal Year 1984. The latest data available according to categories of employment were for Fiscal Year 1982. In Fiscal Year 1982, a total of 226,924 disabled persons were successfully rehabilitated. The break-down that follows only accounts for 215,340.

Type of Closure	Number	Percentage
Competitive	162,473	75.5%
Sheltered Workshop	14,509	6.7%
Self-employed	7,225	3.3%
Homemaker	29,221	13.6%
Unpaid Family Worker	1,912	.9%

The break-down for Fiscal Year 1984 will probably be similar.

The State vocational rehabilitation agency has had much success over the years in the placement of disabled persons into gainful employment. However, more remains to be done. In order to increase the number of persons with disabilities who are placed into gainful employment, vocational rehabilitation agencies must adopt new approaches. Over the past 60 years, employment services in vocational rehabilitation have been geared toward rehabilitating the individual. Vocational rehabilitation agencies must now begin to prepare the labor force to accept disabled workers. Sensitivity training is only one facet of a multitude of strategies needed to integrate persons with disabilities in the work force.

To achieve successful integration in the world of work, rehabilitation agencies must:

1. Work with all employers (private, public, and non-profit organizations).
2. Regard employers as an investment.
3. Be sensitive to the needs of employers and concerned about their satisfaction.

An innovative approach would be to conduct research to identify how employers incorporate disabled workers in the labor force and develop strategies to enhance the capacity of all employers to incorporate disabled workers in the workplace. By building employer capabilities, VR agencies will see increased employment of persons with disabilities.

In addition, State agencies should encourage the Rehabilitation Services Administration to mandate that all RSA funded rehabilitation counselor education programs include employer development, job development, and job placement courses in the curriculum. Counselors in-training should spend time with employers through internship placements in business and industry. In most agencies, the major responsibility for job development and job placement is assigned to the rehabilitation counselor. Existing professional training programs, by and large, do not incorporate placement skills as a major curriculum element. To be effective, programs need to upgrade rehabilitation students' and professionals' abilities in the area of job placement.

Third, the Rehabilitation Services Administration should revise Federal regulations to give State agencies credit for clients who obtain better jobs due to services rendered in Status 32. The current system does not motivate the VR counselor to provide services beyond closure in Status 26. However, Section 154.07 allows the provision of post-employment services to clients who have been closed as rehabilitated.

Very few people continue to work on the initial job for which they were hired. They progress--move up the ladder, so to speak. Disabled individuals should be allowed the same opportunity. In some cases, a short term training program or a new piece of adapted equipment can facilitate career development. The VR counselor who provides these services should receive credit. This change should increase the number of persons with disabilities who will achieve their vocational potential.

2. Title V: Section 501. Section 501 mandates that each Federal agency develop an affirmative action plan for recruiting, placing and advancing handicapped individuals within the agency. Selective placement programs are organized action plans and procedures which provide the framework for Federal agencies to implement this law and other mandates on the hiring, placement and advancement of handicapped persons, disabled veterans, and rehabilitated offenders. For the purposes of Federal employment, a handicapped person is any individual who 1) has a physical or mental impairment which substantially limits one or more major life activities, 2) has a record of such an impairment, or 3) is regarded as having such an impairment.

The programs are designed to assist qualified handicapped individuals--those who are physically impaired, emotionally restored, or mentally retarded, and rehabilitated offenders--to obtain, retain, and advance in employment consistent with their level of skill and abilities and their capacity for safe and efficient job performance. Emphasis is on ability rather than disability and on rehabilitation efforts and present job readiness.

The Office of Personnel Management has the major responsibility for selective placement of handicapped individuals in the Federal Service. There is a selective placement coordinator in every major organizational component of a Federal agency. To plan and implement affirmative action for handicapped individuals, including disabled veterans, any agency or component with at least 3,000 employees should have a full-time program manager or selective placement coordinator.

The operating coordinator is directly involved in the day-to-day aspects of selective placement--from recruitment and interviews to placement, follow-up, and career development. He or she seeks out handicapped individuals who are qualified for Federal employment and helps them find jobs.

There are a variety of special provisions for persons whose disabilities are severe enough that standard procedures become obstacles to Federal employment. Selective placement coordinators should be knowledgeable about each of the following options.

Temporary Trial Appointment. A handicapped individual may profit from an opportunity to show what he or she can do. A temporary trial appointment is one way of overcoming an employer's fear that a person with disabilities will not be able to perform well or will not be accepted by co-workers. Physically handicapped and mentally restored persons can be employed under various temporary trial appointments, the most popular of which lasts 700 hours (approximately four months). There is no grade restriction, and it is not necessary for the agency to set up a special temporary position to use this provision. At the outset the agency makes no commitment for permanent employment, but later an appointment may be made to a continuing position.

Excepted Appointments. For handicapped individuals, appointments in the excepted service differ from those in the competitive service in that the specific position is "excepted" or removed from the competitive system.

This means that an individual's abilities are considered in regard to the tasks of a specific job, not an entire class of positions. In other words, he or she is not in competition with applicants who have established eligibility not only for the position in question but also for similar jobs in the same occupational series.

For Persons with Physical Handicaps. The excepted appointing authority in Section 213.3102(u) of Schedule A was developed to allow employment of physically handicapped persons who are disabled in such a way that they may not be expected to demonstrate their qualifications and obtain an appropriate position through the competitive system. Eligibility for this type of appointment is based primarily on the severity of physical impairment, but consideration also is given to the effect of disability on job performance.

Persons employed under Section 213.3102(u) may be promoted or reassigned within the same agency provided that physical qualification standards are met. After two years of successful employment in the excepted service, an agency may convert employees appointed under this authority, noncompetitively, to career or career-conditional status providing they meet basic eligibilty requirements.

All buildings and facilities owned, leased, occupied or financed by the United States Government should be accessible and usable by physically disabled persons.

Public Law 96-523 authorizes agency heads to employ or assign readers, interpreters and personal assistants for handicapped Federal employees both at their regular duty station and while traveling on official business (OPM, 1981).

For Mentally Retarded Persons. Individuals who are mentally retarded usually are employed in the excepted service under the authority provided by Section 213.3102(t) of Schedule A. Eligible individuals are those with sufficient mental ability, emotional stability, and training to perform in a satisfactory manner the full duties of the position to which they are appointed. For retarded persons, as for other types of handicapped individuals, jobs and work sites may be modified to provide reasonable accomodation of disabilities.

A vocational rehabilitation counselor must certify the employability of the applicant. In effect, this certification is substituted for competitive examination.

Mentally retarded persons may be promoted to any level, provided they are first certified by a counselor for the higher-graded position. However, care should be exercised to assure that individuals are not expected to perform beyond their capacity. Employees appointed under this authority may also be converted noncompetitively to career or career-conditional status after two years of successful employment in the excepted service, provided they meet basic eligibility requirements.

For Mentally Restored Persons. The excepted appointment authority in Section 213.3202(k) of Schedule B was developed to provide mentally restored persons with ample opportunity to update their skills and to establish a successful performance record to counteract prejudice on the part of employers. Eligible individuals are those who are at a severe disadvantage in obtaining employment because of a psychiatric disability as evidenced by hospitalization and/or outpatient treatment and a signficant period of substantially disrupted employment or education and training because of the disability.

In addition, individuals appointed under this authority must meet the minimum qualifications for the position and grade and be certified by either a State or Veterans Administration vocational rehabilitation counselor as being capable of functioning in the specific position.

Appointments under Section 213.3202(k) are for a period not to exceed two years. As this authority will not permit conversion to competitive appointments, individuals wishing to continue in Federal service must compete for any future Federal appointment or have reinstatement eligibility. Prior approval by the Office of Personnel Management of appointments made under Section 213.3202(k) is required.

Numbers Served. According to Equal Employment Opportunity Commission (EEOC), approximately 25,000 individuals with targeted disabilities worked for the Federal Government in Fiscal Year 1983 (targeted disabilities include mental retardation, deafness, blindness, mentally restored, partial paralysis, convulsive disorders, missing extremities, complete paralysis, distortion of limbs/spine).

The Federal Government should provide increased employment opportunities for persons with disabilities. In Fiscal Year 1983, the Federal Government had a work force of 2.9 million. Of this number, there were approximately 25,000 (.86%) individuals with disabilities. The Federal Government must begin to practice what it preaches.

Some actions that could increase the number of disabled persons hired by the Federal Government include:

- The Office of Personnel Management should define the job duties of the selective placement coordinators and qualifications for the position.
- Selective placement coordinators should be required to maintain records of the numbers of persons with disabilities who applied for employment within the Federal agency and the number hired.

- Selective placement coordinators should have knowledge of disability, functional limitations, and accomodations either through formalized training or previous work experience.
- A regulation should be developed to require all Federal agencies that have internship programs to establish annual goals of filling not less than 10% of all internships with disabled individuals with targeted disabilities, including disabled veterans.

3. Title V: Sections 503 and 504. Sections 503 and 504 of the Rehabilitation Act of 1973 have resulted in greater employer awareness about disability. Designed to improve employment opportunities for disabled people, Sections 503 and 504 require employers with more than $2,500 in Federal contracts or subcontracts to take "affirmative action" in hiring and promoting qualified disabled persons. The law further requires employers receiving grants and other Federal financial assistance to be "nondiscriminatory" when considering disabled people for employment. In addition, firms subject to the provisions of Sections 503 and 504 must assure the Federal Government that policies of nondiscrimination are followed in the recruiting, hiring and promoting of workers. Written affirmative action plans are required only of those contractors with 50 or more employees and a contract of over $50,000.

The handicapping condition alone is not reason enough for the person to be covered under Sections 503 and 504. An individual also must be capable of performing a particular job--"with reasonable accommodation" for the handicapping condition. Reasonable accommodation means making necessary adaptions to enable a qualified handicapped person to work. It may include: ensuring that facilities used by employees are accessible to handicapped people (such as installing ramps) and making modifications in jobs, work schedules, equipment or work area (such as changing a person's work schedule so they can avoid rush-hour traffic).

According to a 1982 U.S. Department of Labor Study, the necessary accomodations generally are not expensive. This study, which surveyed 2,000 Federal contractors to determine the nature, extent and cost of accomodations for handicapped employees, found that over half of the 915 firms responding reported no costs incurred for accomodations. An additional 30% (278) of those firms reported costs less than $500, and only 8% (73) of the respondents reported costs more than $2,000.

Many employers find additional benefits from job accomodation. For example, redesigned job tasks frequently are safer and more efficient for both disabled and nondisabled workers; modifications to buildings, such as easily operated doors, benefit nondisabled as well as disabled employees; and the experienced employee who becomes disabled on the job can continue working.

In addition to accomodations, employers are also concerned that insurance rates will skyrocket, safety reports will be jeopardized, and attendance and job performance will suffer. However, E.L. Du Pont de Nemous and Company, Inc., is a private employer which has made a point of hiring workers with disabilities and has monitored their progress in the company. Du Pont conducted a study of its handicapped employees in 1973 and again in 1981. Supervisors were asked to rate handicapped employees on the following: 1) safety, 2) job performance and attendance. In addition, they were asked to compare a sample of their disabled and nondisabled employees. The results for disabled employees:

Safety	Job Performance	Attendance
96% rated average or above average	92% rated average or above average	85% rated average or above average

Du Pont has had no increase in insurance costs. This company has achieved a reputation as an exemplary employer of people with disabilities. The company's reports are replete with examples of successful case stories: messengers who are mentally retarded who have years of perfect attendance, excellent performance records and assist in training new messengers; a computer programmer who is blind; an individual who has multiple birth defects that works as a stenographer; a deaf and speechless man who operates and trains others to use Du Pont's computer assisted machining center. The list goes on and on. Du Pont reports that 2,745 employees are disabled, 2.4% of the work force at Du Pont. Du Pont believes that, if given the opportunity, handicapped employees are equal to the task (Du Pont, 1981).

The Department of Labor's Federal Contract Compliance Program is responsible for enforcing the affirmative action provisions of Section 503. Approximately two million companies are contractors or subcontractors receiving Federal contracts exceeding $2,500. The Employment Standards Administration of the Department of Labor reviews noncompliance in regard to Section 503 and helps employers understand the regulations and develop outreach programs to recruit qualified disabled employees. By 1978, nearly 100 workers had been awarded an approximate total of $330,000 in back pay as the result of Section 503-based decisions by the Department of Labor (Rubin, 1983). Some of the more common violations of Section 503 by Federal contractors include: 1) an inaccessible personnel office and/or worksite; 2) applicant requirements for a job; and 3) failure to use appropriate recruitment sources for informing disabled individuals of the job (Bowe, 1980).

The Office of Civil Rights (within each Federal agency providing the funds) is responsible for the enforcement of Section 504 regulations. Section 504 applies to all organizations and institutions that receive Federal financial assistance (grants) and to each program and activity that receives benefits from the grant. Since the implementation of Section 504 in 1977, many lawsuits have been initiated by persons with disabilities who felt they were discriminated against. The Comprehensive Equal Opportunity Law paper (in this volume) discusses discrimination in the work setting and recommendations to combat this major barrier to employment for persons with disabilities.

4. Title VI: Projects with Industry. Projects with industry (PWI) provide handicapped individuals training and employment in a realistic work setting to prepare them for employment in the competitive market. Funds are authorized to allow the Commissioner of the Rehabilitation Service Administration to enter into agreements with individual employers and other entities to establish jointly funded projects in the private sector. Projects are designed to provide support services and expand job opportunities for handicapped workers.

PWI is a private business initiative involving employers, labor organizations, trade associations, foundations and voluntary agencies which operate through a partnership arrangement with persons in the rehabilitation field to create and expand job opportunities for handicapped persons in the competitive labor market.

Prior to 1978, authorization for these projects was part of a large discretionary authority under which funds could be used for projects and demonstrations to address a variety of special vocational rehabilitation needs of handicapped persons. First funded in Fiscal Year 1970 at $900,000, the projects were initiated in an effort to involve the business community in the rehabilitation process. By Fiscal Year 1977, 4,800 disabled persons, most of whom were severely disabled, received services in over 30 projects that were affiliated with more than 1,200 private corporations.

The 1978 amendements to the Rehabilitation Act established a new title: Title VI - Employment Opportunities for Handicapped Individuals. Section 621 provides separate authority for the projects with industry program. Since these amendments, the program funding has nearly tripled from $4.5 million in Fiscal Year 1979 to $13.0 million in Fiscal Year 1984. In Fiscal Year 1985, the program funding was $14.4 million.

There are some 250 projects nationwide; however, 99 of these receive RSA funding. In Fiscal Year 1984, approximately 14,000 disabled people, most of whom were severely disabled, received employment service under the program. Ten thousand five hundred of these individuals moved into competitive employment.

Each PWI consists of a linkage to the private sector, a training site, and a source of clients. The employer advisory committee is the link to business/industry. The training site is generally a rehabilitation facility, and the State vocational rehabilitation agency certifies client status and their eligibilty for services. Using this framework, PWI projects have evolved into the following models:

- The Job Placement Model: uses job matching to generate employment opportunities for work-ready disabled people.
- The Work Adjustment Model: provides temporary, realistic work experience and job-seeking skills to disabled persons.
- The Skill Training Model: offers severely disabled people the opportunity to acquire new technical skills required for jobs in the labor market.

As intended by Congress, the PWI program creates an active partnership among business, industry, and rehabilitation service agencies; makes rehabilitation services more responsive to employer needs; and facilitates the utilization of the untapped potential of handicapped people as resources (IRI, 1983).

B. Job Training Partnership Act (Public Law 97-300)

The purpose of the Job Training Partnership Act is "To establish programs to prepare youth and unskilled adults for entry into the labor force and to afford job training to those economically disadvantaged individuals and other individuals facing serious barriers to employment who are in special need of such training to obtain productive employment."

The Job Training Partnership Act performance standards emphasize high placement rates, low costs per placement, and high average wages at placement. This emphasis left many local program operators initially reluctant to serve in large proportions hard-to-serve individuals (such as disabled people) who require longer, more expensive training and who are more difficult to place in competitive employment. However, a National Alliance of Business analysis of the Job Training Partnership Act (JTPA) program data for 1984 shows the majority of local programs met most of their performance standards. That very positive record offers local programs some important planning guidance: the system can target hard-to-serve groups, including disabled people, and serve them well without jeopardizing its overall performance record.

The data available from the Department of Labor for 1984 provides no information about the percentage of persons with disabilities who were

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served by the JTPA. As was discussed above in the Transition Section, JTPA probably is not adequately serving people with disabilities.

C. Randolph-Sheppard Vending Act (Public Law 74-732 and Amendment)

The Vending Facility Program authorized by the Randolph Sheppard Act, as amended, provides blind persons with remunerative employment and self-support through the operation of vending facilities located on Federal and other property. The State rehabilitation agency serves as the State licensing agency. Thousands of blind individuals have been provided business opportunities through the Randolph-Sheppard Act.

In Fiscal Year 1983, 3,261 vending facilities (974 located on Federal property and 2,287 on non-Federal property) provided employment for 3,677 blind vendors (1,100 on Federal property and 2,577 on non-Federal property. Gross income from all facilities totaled $279.6 million in Fiscal Year 1983. The national average annual earnings of all vendors was $17,308 in 1983. Additionally, Randolph Sheppard program provides employment opportunities for other disabled and disadvantaged individuals as cashiers, cooks, assistants and middle management positions.

D. Wagner-Peyser Act of 1933 (As Amended)

The Wagner-Peyser Act of 1933, as amended, authorizes the establishment and operation of the Federal-State employment security system to help individuals find jobs and assist employers in locating qualified workers. Amendments to the Act in 1954 expanded the program by requiring every local employment service (or job service) office to designate at least one staff member as responsible for helping severely handicapped individuals locate training resources and/or suitable employment.

Applicants are considered handicapped if they have physical, mental or emotional impairments that constitute an obstacle to their employment. Alcohol and drug abusers are included. The goals of the Employment Service's program for handicapped persons cover: 1) equal opportunity for employment and equal pay in competition with other applicants; 2) employment at the highest skill level permitted by their occupational qualifications; 3) satisfactory adjustment to chosen occupations and work situations; and 4) employment that will not endanger others or aggravate the individual's disability(s). The Act also requires State employment services to coordinate their activities with State vocational rehabilitation agencies.

More than 2,000 Employment Service Centers are located throughout the United States. Available data on the number of of handicapped persons served under this Act are for Fiscal Year 1981. During that year, counseling and placement assistance were the main services provided to handicapped applicants. Handicapped applicants accounted for 4% of all applicants; 152,000, or 21% of those who registered were placed in jobs (DOL, 1982). As indicated by these figures, the placement of persons with disabilities by the Employment Service Centers has been extremely low.

E. Targeted Jobs Tax Credit (TJTC)

The Targeted Jobs Tax Credit Program (Deficit Reduction Act of 1984) provides tax credits for employers of disabled individuals.

The tax credit is 50% of the qualified first-year wages up to $6,000 and 25% of the qualified second-year wages up to $6,000 for each eligible employee. This provides up to $4,500 in Federal tax credits for each eligible employee. Eligible employees include:

1) vocational rehabilitation referrals
2) economically disadvantaged youths
3) economically disadvantaged Vietnam-era veterans
4) Supplemental Security Income (SSI) recipients
5) General Assistance recipients
6) youths participating in a cooperative education program
7) economically disadvantaged ex-convicts
8) involuntarily terminated Comprehensive Employment and Training Act (CETA) employees who started work for the employer after August 13, 1981, and before January 1, 1983
9) eligible work incentive employees or
10) qualified summer youth employees.

In order for an employer to claim tax credit on wages paid to a (newly-hired) employee, that employee must be certified as a member of a targeted group by the designated local agency (generally the local office of the State Employment Services Agency). In some States this certification authority is delegated to the State Rehabilitation Agency (for certification of persons with disabilities).

Number Served. In Fiscal Year 1984, 563,381 persons were certified under the Targeted Jobs Tax Credit Program. Of that number, 38,263 were vocational rehabilitation referrals (disabled individuals) (U.S. Department of Labor, 1985). The U.S. Treasury Department and the Department of Labor have conflicting data about the cost of this program to the government.

F. Section 190 of the Tax Code

The Tax Reform Act of 1976 (P.L. 455) (included in the Deficit Reduction Act of 1984) reauthorized Section 190 of the Internal Revenue Code. Under Section 190, businesses are permitted to deduct up to $35,000 for costs incurred in removing architectural and transportation barriers to the elderly and handicapped persons in any facility or public transportation vehicle owned or leased for use in a trade or business. The new tax deduction provisions of Section 190 of the code are applicable for expenses incurred during the taxable years of 1984 and 1985. Data have not been collected on the cost of this deduction to the government.

G. Social Security Act - Title II - Section 222: Rehabilitation Services

The Social Security Program is regarded as an income maintenance program. However, one of the major objectives of both Title II (Social Security Disability Insurance) and Title XVI (Supplemental Security Income) is to encourage the rehabilitation of disabled people and assist them in entering or returning to productive employment.

A complete discussion of Titles II and XVI is included in the "Disincentives" paper that is included in this volume. A summary of the provisions related to rehabilitation and employment are discussed below.

Sections 222 and 1615 of the Social Security Act provide for the payment from Federal Trust Funds for the costs of vocational rehabilitation services to disabled SSI and SSDI beneficiaries. In Fiscal Year 1980, $113 million and $55 million were available respectively for SSDI and SSI recipients under the Beneficiary Rehabilitation Program. However, because of significant legislative changes, funding has decreased significantly under these provisions to about $2.2 million in each of Fiscal Years 1983 and 1984.

The Beneficiary Rehabilitation program was changed drastically by the Omnibus Budget Reconciliation Act of 1981 in a way that created severe disincentives to severely disabled persons. Prior to this Act, vocational rehabilitation agencies were reimbursed for services provided to SSDI and SSI clients, regardless of outcome. The 1981 Act, however, changed this to a performance reimbursement system so that vocational rehabilitation agencies are paid only if the client is sustained in employment paying SGA wages for a continuous period of five months.

This system creates a long time period between the provision of services and reimbursement to the States. It also discourages agencies from serving severely disabled persons who require lengthy periods of rehabilitation services, who do not have a high probability of earning above the SGA level, and who may require extensive long-term vocational support.

The Rehabilitation Services Administration and the Social Security Administration have conflicting data on the number of disabled persons rehabilitated under the Beneficiary Rehabilitation Program. However, both agree that there has been a decrease in services to SSI and SSDI beneficiaries.

Changes need to be made in the reimbursement system so that SSI and SSDI beneficiaries receive adequate rehabilitation services. One strategy to improve the system would be cost-sharing for services provided, regardless of outcome.

H. Disabled Veterans Programs

A number of special programs help meet the employment needs of veterans with disabilities. Some are available through the Veterans Administration (VA), while others are available through other agencies that serve all persons with disabilities.

VA programs have an enormous impact on the lives of millions of Americans. Congress appropriated $26.5 billion in Fiscal Year 1984 to ensure that the Agency would provide benefits and services to the nation's veterans and their dependents. Approximately 60% of the VA budget in Fiscal Year 1984 was allocated to fund benefit payments under Department of Veterans Benefits (DVB) programs, including compensation and pension, education, loan guarantee and vocational rehabilitation. Almost $14 billion was authorized to fund monthly compensation and benefit payments to 4.3 million veterans and survivors.

The VA provides many services; however, this section highlights only the Vocational Rehabilitation and Counseling Program.

1. The Department of Veterans Benefits (DVB). DVB provides benefit counselors at more than 200 locations throughout the United States, Puerto Rico and the Republic of the Phillipines. Included in this number are 58 fully staffed regional offices which provide VA benefits to the local population of veterans and their survivors. All 58 regional offices employ counseling psychologists and vocational rehabilitation specialists who assist service-connected disabled veterans to use their VA benefits in the development and completion of formal rehabilitation plans.

The primary mission of Vocational Rehabilitation and Counseling (VR&C) is to provide all services and assistance necessary to enable veterans with service-connected disabilities to achieve maximum independence in daily living and, to the maximum extent feasible, become employable and to obtain and maintain suitable employment. Service-connected disabled veterans who are eligible for these services are identified and encouraged by local VR&C staff members to apply for rehabilitation benefits.

2. Two New Initiatives at the VA. Two special pilot programs were established to help severely disabled veterans qualify for, obtain and maintain employment. Both programs were initiated on February 1, 1985, and will be in effect through January 31, 1989. All nonservice-connected disabled veterans added to the pension rolls during that period will be eligible for consideration of their ability to profit from vocational training. A veteran will continue to receive a pension during the period of training and employment services, although his or her pension will be reduced or terminated following adjustment in employment when work income exceeds the annual income limitation applicable to the pension. VA health care eligibility is preserved for a three year period following the date on which the pension is terminated due to income from work or training.

In the second new program, the total disability compensation rating based on individual unemployability of all service-connected disabled veterans who secure employment is protected for 12 months. Vocational training and/or employment services are available to assist these veterans to train for and secure employment.

Vocational Rehabilitation and Counseling has broadened its authority by offering programs consisting only of employment services to job-ready veterans. Prior to this change, service-connected disabled veterans were required to participate in training under either the VA or State vocational rehabilitation programs (Wyant, 1985).

According to Wyant (1985), in Fiscal Year 1985, 30,000 disabled veterans were enrolled in training. The majority were Vietnam-era veterans. Five thousand of these veterans developed employment plans; 70% are expected to go to work in a reasonable period of time.

3. Disabled Veterans Outreach Program. The Disabled Veterans Outreach Program (DVOP) was initiated as a temporary program in June 1977 as part of the Economic Stimulus Package. Passage of the Veterans Rehabilitation and Education Amendments of 1980 (P.L. 96-466) provided for a permanent Department of Labor-funded program.

The major objective of the Disabled Veterans Outreach Program is to locate jobless, disabled Vietnam-era veterans and assist them in obtaining suitable employment and/or training. Disabled Veterans Outreach Program staff develop employer contacts and work with community groups and local veteran's organizations to identify disabled veterans and to develop job opportunities for them in both the public and private sector. DVOP staff have contributed to the placement of more than 160,000 disabled veterans since the inception of the program in Fiscal Year 1984. Data was not available for Fiscal Year 1985.

4. Emergency Veterans Job Training Act of 1983 (P.L. 98-77). This Act was passed by Congress in October, 1983 and responsibility for implementation is shared by the Veteran's Administration and the Department of Labor. It provides employment opportunities for the long-term unemployed veteran of the Vietnam or Korean War. In order to qualify, a veteran must have been unemployed for at least 15 weeks of the past 20 weeks prior to applying for certification. The veteran registers at the Employment Service Center and is then certified by the Veteran's Administration. The Department of Labor matches the veteran with the job.

The Veteran's Administration is also responsible for certifying employers. Employers must have training programs available, primarily on-the-job training. The veterans participate in the training for the first six months (or nine months in the case of disabled veterans). The training (position) must lead to full-time, permanent employment. The employer receives one-half the starting wages up to $10,000 of the first year's wages.

The program begin in November 1983 with no operational funds appropriated. Subsequently, Congress appropriated $150 million for employers. The goal was to place 30,000 veterans into employment; however, more than 45,000 veterans have found employment as a result of this program, representing a 35% increase over goal. Unless this Act is extended, no additional veterans will be certified. Currently 97,000 veterans are certified eligible (veterans must certify every 60 days). Employers have until July 1, 1986 to initiate the training programs in order to qualify.

Data were not available on the number of veterans with disabilities who were placed by this program. However, this program is doing an outstanding job of creating employment opportunities for veterans and should be continued.

I. President's Committee on Employment of the Handicapped

The President's Committee on Employment of the Handicapped, a coalition of national organizations and individual volunteers who have pooled their resources and efforts for the economic and social betterment of physically and mentally disabled workers, has as its goals:

- the creation of a more favorable climate of acceptance of handicapped individuals
- the elimination of barriers and the creation of pathways to employment for handicapped workers
- the more complete assimilation of handicapped citizens into the life of their community (Posner, 1984).

The President's Committee sponsors an annual conference that brings together persons with disabilities, professionals in the field of rehabilitation, parents and employers. In addition, the President's Committee conducts public awareness programs that describe persons with disabilities and their ability to work. A variety of publications related to employment are published by the President's Committee.

Recently, the President's Committee on Employment of the Handicapped established a nationwide computerized network of information on how employers have made accomodations to functional limitations of disabled workers, thus enabling them to be employed or to return to work. The Job Accommodation Network (JAN) is organized for employers by employers. JAN offers a free data base of information about what companies have done to meet special needs. For example, an employer trying to help a paralyzed line manager return to work can learn how other organizations adjusted similar jobs to comparable limitations. JAN puts employers in touch with other employers. The benefit/cost ratio is particularly favorable when an accommodation allows an injured employee to return to work. Accommodations usually are not expensive. This computerized data base is located at West Virginia University. It receives financial support from the National Institute of Handicapped Research and the Rehabilitation Services Administration.

J. Non-Profit Organizations and Agencies

Hundreds of national non-profit organizations and agencies assist persons with disabilities to become gainfully employed. Three are highlighted below.

1. Association for Retarded Citizens (ARC). ARC was organized in 1950, primarily by parents. Since that time, the Association has grown into a membership of over 160 thousand. Local ARC's are located across the United States, providing an array of services to retarded citizens. The Association for Retarded Citizens will reimburse the employer for the first 320 hours of employment of a mentally retarded person hired through the Association in a major on-the-job training program. ARC pays one-half of the person's wages for the first 160 hours of work and one-quarter for the second 160 hours. ARC has placed over 35,000 mentally retarded individuals since beginning the OJT program in July, 1967.

2. Mainstream, Inc. Mainstream is a non-profit organization based in Washington, D.C. It was founded in 1975 to aid handicapped individuals by helping employers create an accessible environment for handicapped persons and meet compliance demands of recent legislation. Mainstream's compliance consultation services include accessibility surveys of facilities. They have found that many barriers have nothing to do with accessibility; that is, costs to employers are usually far less than assumed--perhaps as low as one cent per square foot.

Mainstream provides a national referral service available to employers and persons with disabilities. Also it teaches organizations how to use job analyses to match up the abilities of potential employees with the job, instead of redefining the job. It provides information on qualified applicants with disabilties. Information services include a quarterly newsletter, a hotline for compliance questions, national and regional conferences on hiring, and seminars on interview techniques and human relations training.

3. Goodwill Industries. Goodwill Industries is a very familiar, national name. Most Goodwills provide personal and work adjustment training,

vocational training, and employment in sheltered workshops and in competitive settings. In Fiscal Year 1984, Goodwill Industries (nationally) placed into competitive employment more than 11,000 persons with disabilities.

K. Private Sector Initiatives

The in-house return to work programs at the following three major companies are reflective of what some private companies are doing to hire and retain persons with disabilities in employment.

1. Minnesota Mining & Manufacturing Company (3M). For the past 12 years, the Minnesota Mining & Manufacturing Company has had a rehabilitation project called the Disability Management Program. The company has hired a licensed psychologist and a certified rehabilitation counselor to run it. 3M chose this route because its own staff is always available, can readily identify employees who need help, is familiar with company structure, has quick access to information and can easily provide follow-up services to rehabilitated employees.

The Disability Management Program focuses on current 3M employees. The goal of the program is to have employees who become disabled receive the therapeutic and rehabilitative services that will enable them to stay on the payroll and work to full capacity. The program stimulates production and controls insurance rates and disability payments. 3M believes that its internal program is cost effective. Smaller companies would need to rely more on help from rehabilitation agencies, but could count on getting similar results.

2. Control Data Corporation. The Control Data Corporation runs a selective placement and rehabilitation program for disabled employees. Control Data's objectives are to prevent the waste of human resources, to maintain productivity, and to save on disability payments. The Corporation is satisfied that its program is meeting all three objectives.

Control Data calls part of its program "Homework." It is an example of how a corporation can put its own technology to good use for itself as well as for its disabled employees. Homework provides training through the PLATO computer-based education system and then employment. A PLATO terminal can be installed in anyone's home and linked to terminals at the office or at nearly any other location.

The economic benefits to the company are substantial. The psychological benefits to employees are inestimable (Pati & Morrison, 1982).

3. Sears, Roebuck and Company. Sears, Roebuck and Company presents its programs in its excellent Selective Placement Program and Manual, which is given to all the company's supervisors and managers. It covers company policy, recruitment sources, the interviewing and hiring process, record keeping, audits and reviews, the affirmative action plan, a definition of cases that require physical examinations, access to the facilities, and information on each unit's disabilities and disabled employees. The manual reveals the thoroughness and commitment that make the program work.

All Sears employees complete a selective placement survey that gives them an opportunity to identify their disabilities. The company processes the surveys and codes them for disability and accommodation. Most accommodations entail little expense for the company. Accommodations can be made at little or no cost or inconvenience but with considerable benefit to both employees and employers.

As illustrated by these companies and a long list of others, businesses are discovering that hiring persons with disabilities and/or establishing return-to-work programs for employees who develop disabilities make good business sense.

It is best summed up by the comments of Colby H. Chandler, Chairman and Chief Executive Officer, Eastman Kodak Company: "American industry finds itself with an opportunity--a rich resource in the 35 million Americans described as disabled. Hiring and training men and women who are disabled is clearly a plus--for companies, for those eager to help themselves, and for our economy" (PCEH, 1985).

L. Gaps in Legislation and Programs

Following are some of the gaps in legislation and programs that create barriers to persons with disabilities becoming gainfully employed.

1. Lack of Incentives for Employers to Hire Persons With Disabilities. More than 80 percent of the job vacancies existing today are in the private sector.

Employers must be motivated to hire disabled persons. Even though some companies such as Kodak, DuPont, IBM, 3M, Control Data, and AT&T have made concerted efforts to hire and retain persons with disabilities, other companies need to be convinced that employing persons with disabilities is good business.

The attitudes, discrimination, myths, prejudice and stereotypes that exist among some employers affect the disabled person's entry into the labor market. It has long been a truism in the rehabilitation field that the major barrier to employing the handicapped is the negative attitudes (nurtured by the twin bogeys--fear and ignorance) of the employers (Pati, Adkins & Morrison, 1981). The authors examined two studies and found the adage to still be true. However, employers working through PWI's had improved attitudes regarding the hiring of persons with disabilities.

Research studies indicate a wide range in attitudes among employers which, in effect, can be considered as authentic or false (unrealistic) positive stereotypes, or negative stereotypes, which can consequently create employer prejudice and employer discrimination against disabled persons (Schroedel & Jacobsen, 1978).

2. Lack of Upward Mobility for Disabled Persons Placed into Employment. Most persons with disabilities are placed into entry level positions. In order to be promoted, in some cases additional training may be needed or a piece of equipment provided. Who provides this training? Who pays for this piece of equipment? There have been cases reported where persons with disabilities have remained in the same entry level positions for more than twenty years.

3. The Need For Well Trained Rehabilitation Professionals. In most State agencies, the vocational rehabilitation counselor has the responsibility of placing the client into employment. Counselors must be skilled in job development and job placement techniques and have the ability to work effectively with the business community. A large number of counselors are inadequately trained in the area of job development and job placement. Some are uncomfortable with contacting the employment community.

4. Work Disincentives Posed by SSI and SSDI. The average income of a SSDI recipient is $456 per month; $345 for a SSI recipient. The recipients also receive Medicare or Medicaid. The thought of becoming employed and

losing a stable income and medical benefits is very difficult for a disabled individual who receives SSI or SSDI benefits.

In order for the individual to consider working, the salary must be considerably higher than the benefit, and the company must offer group health insurance (a lot of insurance companies do not provide coverage for persons with disabilities). The thought of losing medical benefits often prevents a disabled SSDI or SSI beneficiary from entering the workforce or returning to work.

Additionally, workers' compensation can also be regarded as a disincentive. Workers injured on the job may not return to work for the fear of losing benefits.

5. Inaccessible Work Environments. Due to inaccessible transportation, buildings and job sites, persons with disabilities often are unable to function independently and become gainfully employed. Being able to get to work is a prerequisite for all persons who want to work. Inaccessible transportation is a major problem for disabled people who want to work.

6. Inadequate Service Provision to Persons with Disabilities Under the Job Training Partnership Act. Data were not available on the number of disabled persons served. However, the feeling exists that disabled persons are receiving less services under JTPA than CETA. Disabled persons are not eligible based upon their disabilities, but must meet income eligibility criteria. Disabled persons must meet an income level unless treated as a single household.

7. The Need For a Coordinated and Organized Selective Placement Program and Trained Selective Placement Coordinators in the Federal Government. Selective placement coordinators are not required to maintain records on the number of persons with disabilities recruited or hired within their

respective agencies. Also, it is difficult to find out from selective placement coordinators the number of persons with disabilities who are employed within the agency.

For the most part, selective placement coordinators are promoted from clerical positions and/or may perform many other duties in addition to serving as the selective placement coordinator. Some selective placement coordinators may not possess a knowledge of disabilities, functional limitations and issues effecting job accommodations. There is no agreement within agencies on where the selective placement coordinator should be located. The selective placement coordinator usually is housed either in the personnel office or in the Office of Equal Opportunity.

V. SHELTERED EMPLOYMENT

In society today, a large number of disabled persons have disabilities so severe that employment in a competitive setting is a distant and often unrealistic goal. For this group of disabled individuals, employment, if any, is found primarily in the noncompetitive setting or sheltered workshops.

Since 1963, the Federal Government has taken many actions to improve employment opportunities and labor standards for persons with severe disabilities. As the demand for community services for persons with disabilities increased, sheltered workshops played an important role by providing both training and employment for severely disabled persons (as defined in the Rehabilitation Act).

Approximately 4,000 sheltered workshops provide employment, evaluation, training and other rehabilitation services to about 200,000 severely disabled persons daily. Because of the current movement of persons out of institutions and into community settings, many more individuals with mental disabilities are in need of community-based employment and training services (GAO, 1981).

A wide range of training and job preparation programs are available to disabled persons, depending on their level of education, vocational potential, and previous employment experience. For severely disabled persons, however, these services are likely to be limited to programs provided in work activities centers, developmental centers or other sheltered workshops. Some severely disabled persons may move into competitive employment in the community after training, but most, because of the severity of their handicapping condition, require long-term training and sheltered employment.

Although the term sheltered workshop is commonly used, it does not have a common meaning. In this paper, a sheltered workshop is any vocationally oriented rehabilitation facility which provides 1) training, including sheltered employment for severely disabled workers who have potential for competitive employment, or 2) full-time employment for severely disabled persons who cannot move from sheltered into competitive employment. Sheltered workshops provide a controlled, work-oriented environment to assist handicapped persons develop their optimal level of vocational and social functioning.

A. Legislation and Programs

The Federal Government has played a major role in the growth and development of sheltered workshops, including providing a variety of funding sources, establishing special procurement opportunities and regulating workshop employment practices and procedures.

1. Federal Financial Assistance for Sheltered Workshops. Enactment of the Mental Retardation Facilities and Community Mental Health Centers Construction Act (Public Law 88-164, 77 Stat. 282) in 1963 provided the basis for a major Federal effort to develop and improve services for severely handicapped people. The Act provided for Federal assistance in establishing sheltered workshops for mentally retarded persons through grants for new construction and expansion of existing buildings, employing staff, and purchasing equipment.

The 1965 Amendments to the Vocational Rehabilitation Act (Public Law 89-333, 70 Stat. 1282) authorized a comprehensive program of Federal financial assistance for rehabilitation facilities (including sheltered workshops), established a technical assistance program for improving workshops, and mandated statewide planning of sheltered workshops and other rehabilitation facilities.

Enactment of the Developmental Disabilities Services and Facilities Construction Amendments of 1970 (Public Law 91-517, 84 Stat. 1316) also provided for statewide planning of services and facilities for persons with developmental disabilities as well as Federal financial assistance for providing services and developing facilities, including sheltered workshops.

Amendments of the Social Security Act in 1967, 1972, and 1974 provided Federal financial assistance for social services for handicapped persons who were recipients or potential recipients of public assistance. Through these amendments, sheltered workshops received Federal funds for providing rehabilitation and social services for improving the level of economic independence or employability of handicapped persons.

The passage of the Rehabilitation Act of 1973 (Public Law 93-112, 87 Stat. 355) provided for a wide variety of rehabilitation services for severely handicapped persons. Under the 1973 Act, Federal funds were used for establishing and conducting vocational rehabilitation programs for assisting disabled persons to prepare for and engage in competitive employment to the extent of their capabilities. State rehabilitation agency staff provide referral, counseling and guidance, and placement services. They also coordinate and authorize the acquisition of needed services from other public programs or purchase the required services on a fee-for-service basis from the private sector, including sheltered workshops or rehabilitation facilities.

Sheltered workshops also receive Federal funds through programs established by other Federal laws, including the Vocational Education Amendments of 1968 (Public Law 90-576, 82 Stat. 1064) for funding staff or providing services for training the handicapped; the Small Business Investment Act Amendments of 1972 (Public Law 92-595, 86 Stat. 1314) for financial assistance, through loans or loan guarantees, for producing and marketing commodities and services; the Rehabilitation, Comprehensive Services and Developmental Disabilities Amendments of 1978 (Public Law 95-602, 92 Stat. 2955) for providing services or developing facilities; and the Comprehensive Employment and Training Act of 1973 (Public Law 93-203, 87 Stat. 839) (currently JTPA) for providing job training and employment for economically disadvantaged, unemployed, or underemployed persons.

2. Employment Opportunities in Sheltered Workshops. The Wagner-O'Day Act, as amended (Public Law 92-28, 85 Stat. 77), created the Committee for Purchase from the Blind and Other Severely Handicapped to establish a list of suitable products and services which the Federal government must purchase from designated sheltered workshops. The original law, enacted in 1938, required procurement only from workshops for the blind. However, amendments in 1971 extended coverage to sheltered workshops serving other severely handicapped persons. The Committee's primary purpose is to increase employment opportunities for blind and other severely handicapped persons.

In 1980, amendments to the Small Business Act (Public Law 96-302, 94 Stat. 839) authorized public and private nonprofit organizations to participate in the small business set-aside program. The set-aside program is administered by the Small Business Administration and is designed to increase the number of Federal contracts awarded to small businesses. Under this program, the Small Business Administration works with Federal procurement agencies to identify commodities and services which do not require large facilities, organizations, or investments for the bidder to be competitive. The law limits the participation of public and private nonprofit organizations, including sheltered workshops, to Fiscal Years 1981, 1982, and 1983. Also, the total amount of set-asides for these organizations may not exceed $100 million in any year.

3. Protection of Wages of Disabled Workers in Sheltered Workshops. The Fair Labor Standards Act of 1938, as amended, established provisions and standards for recordkeeping, minimum wages, overtime pay, child labor, and equal pay. These basic requirements apply to employees engaged in interstate commerce or in the production of goods for interstate commerce. The Act provides special exemptions[3] from its requirements for workers employed in certain occupations or establishments, including sheltered workshops. For example, the Secretary of Labor is authorized to issue special certificates for employing handicapped workers in sheltered workshops at wages lower than the statutory minimum (now $3.35 an hour) to encourage sheltered workshops to hire handicapped workers who are not capable of earning the statutory minimum because of low productivity. Under the Act, the wages paid handicapped workers in sheltered workshops must be commensurate with those paid nonhandicapped workers in local industry for essentially the same type, quality, and quantity of work. Labor is also responsible for monitoring sheltered workshops' compliance with the Federal standards.

The Service Contract Act of 1965, as amended, provides labor standards protection for employees of contractors furnishing services to the Federal Government. Some examples of services covered under the Act include laundry and dry cleaning, mail transportation, custodial, janitorial, grounds maintenance, security and guard services, packing and crating services, cafeteria and food service, aerial survey, ambulance services, equipment repair and maintenance services, inventory services, linen supply services, lodging services, support services at military installations, drafting and illustrating services, computer operation and repair, keypunching services, warehousing or storage services. Under the Act, workers performing services under a Federal contract must receive wages not less than the minimum wage specified under the Fair Labor Standards Act and, for contracts exceeding $2,500, the minimum wages and fringe benefits must be based on rates determined by the Secretary of Labor to be prevailing for service employees in the locality.

The Walsh-Healey Public Contracts Act provides labor standards protection for employees of contractors manufacturing or furnishing materials, supplies, articles, and equipment to the Federal Government for all contracts exceeding $10,000. Under the Act, employees must be paid wages not lower than the minimum wages determined by the Secretary of Labor to be prevailing in the locality in which the materials, supplies, articles, or equipment are to be manufactured or furnished under the contract. In the absence of a higher minimum wage, the minimum rate established by the Fair Labor Standards Act must be paid.

4. Sheltered Workshops. Sheltered worshops are established and operated at the State and local levels to address rehabilitation and employment needs of persons with disabilities. Although sheltered workshops primarily serve persons with disabilities, some workshops serve only clients with a specific disabling condition, while others serve clients having a broad range of disabilities. While the types of disabling conditions may

vary considerably, the major disability groups include mentally retarded, mentally ill, visually impaired, and orthopedically handicapped individuals. According to the Department of Labor's March 1979 study of sheltered workshops (based on a 1976 personal interview survey), persons with mental disabilities comprise 83% of the workshop population, physically disabled workers account for 10% and socially disabled workers for 7%. Although sheltered workshops are the principal, and often the only, source of employment for severely disabled people, sheltered workshops do not necessarily employ only workers with disabilities. Many sheltered workshops employ, on a full- or part-time basis, nondisabled workers.

Most workshops provide a wide range of vocational and rehabilitation services, such as:

-- evaluation (testing, vocational determination, or continuing review of development),

-- work adjustment training (acceptance of supervision, cooperating with fellow workers, or developing good work habits),

-- vocational training (developing or improving occupational skills), and

-- placement services.

At some workshops, the range of services provided is very limited.

Generally, sheltered workshops are classified as either a 1) regular workshop program or 2) work activities center. A regular workshop program is one in which the employment opportunities for persons with disabilities are stressed. In contrast, a work activities program is generally defined as a center which is planned and designed exclusively for providing therapeutic activities for persons with disabilities whose physical or mental impairment is so severe as to make their productive capacity inconsequential.

In work activities centers, the primary emphasis is on therapy rather than on work (GAO, 1981).

According to the Department of Labor's statistics, there were 1,689 regular workshop programs and 3,079 work activities centers at the end of Fiscal Year 1979. In many instances, a rehabilitation facility will operate both a regular workshop program and a work activities center. Labor's statistics show that 3,877 organizations operated a regular program, a work activities center, or both at the end of Fiscal Year 1979. However, Labor's statistics overstate the number of individual organizations operating sheltered workshops because Labor considers each branch location as a separate workshop. Some workshops operate totally from a central location, and others operate as many as nine branch or satellite locations.

State vocational rehabilitation agencies place clients that they consider incapable of normal competitive employment in extended employment in sheltered workshops. Most are severely disabled, and many are mentally retarded. Severely disabled persons are placed in sheltered employment after receiving vocational rehabilitation services, such as evalution, training, counseling, and medical services.

To assure that these former vocational rehabilitation clients do not remain in sheltered employment longer than necessary, the Rehabilitation Act of 1973 requires that their potential for competitive employment be periodically reevaluated. The Act requires that each State provide for 1) periodic review and reevaluation of the status of individuals with disabilities placed in extended employment in sheltered workshops to determine the feasibility of their employment, or training for employment, in the competitive labor market, and 2) maximum efforts to place workshop participants in employment or training whenever feasible.

Data was not available on the number of disabled persons reevaluated and placed into competitive employment by vocational rehabilitation in Fiscal Year 1984. However, in Fiscal Year 1982, 14,509 clients were closed in sheltered employment by State vocational rehabilitation agencies.

No clear, concise data are reported on or by sheltered workshops. Different organizations keep various data depending on their needs. For example, the National Industries for the Severely Handicapped (NISH), which is a nonprofit organization that provides technical assistance to sheltered work centers interested in securing Federal contracts under the mandatory procurement provisions of Public Law 92-28, the Javits-Wagner-O'Day Act, maintains data on procurement.

NISH was organized in 1974 at the suggestion of Congress. Its establishment was supported by a coalition of national agencies long connected with serving handicapped individuals. They are:

- Association for Retarded Citizens
- Goodwill Industries of America
- National Association of Jewish Vocational Services
- National Association of Rehabilitation Facilities
- National Easter Seal Society
- United Cerebral Palsy Associations

The primary objective of NISH is to provide jobs for severely disabled people and promote their placement into competitive industry.

The following is the Annual Configuration Statistics reported by NISH for Fiscal Year 1984.

	JWOD CONTRACTS	NON-JWOD CONTRACTS	TOTAL AGENCY
WAGES			
Direct labor wages paid to severely handicapped individuals	$19.8 m	$33.1 m	$52.9 m
Average hourly wage paid to all severely handicapped individuals	$ 3.50	$ 1.48	N/A
Average hourly wage paid to severely handicapped individuals in WAC's	$ 1.76	$ 0.93	N/A
Average hourly wage paid to severely handicapped individuals excluding those people in WAC's	$ 4.10	$ 2.19	N/A
JOBS/PEOPLE			
Number of severely handicapped individuals employed	10,365	37,990	48,355
Percent of blind individuals employed (including blind and other handicap)	1.1%	1.5%	1.4%
Percent of severely handicapped individuals placed in competitive employment	9.8%	10.3%	9.8%
Severely handicapped direct labor ratio	85/15	N/A	91/9
SALES			
Agency Sales	$85.3 m	$132.1 m	$217.4 m

N/A - Information not applicable or not available from the data submitted.

A significant portion of government procurements are made by State and local governments. Many States have longstanding programs mandating purchases from prison industries. These laws, known as "State use laws," are usually applicable to products produced in State prisons. While State public work laws are applicable to services under the rubric of State use laws, approximately 40 States have also included products and services provided by disabled workers. Other States created freestanding legislation directed solely at improving employment opportunities for disabled workers.

One of the most successful and well established programs is Industries for the Blind of New York State, Inc. In 1983, annual sales of the 10 facilities exceeded $5 million. Items such as maintenance equipment, maps of various sorts, brooms, miscellaneous brushes, textile products, flags, reflective safety equipment and vinyl portfolios are purchased by the State of New York and distributed throughout State agencies.

B. Gaps in Legislation/Programs

The following major gaps exist in legislation and/or programs that focus on sheltered employment.

(1) Persons with disabilities who are placed into sheltered employment are often left in the setting without reevaluation to determine if they can move into competitive employment. Often workshop staff retain the best workers in order to keep productivity at a high level.

(2) Sheltered workshops are allowed under the Fair Labor Standards Act to pay disabled workers at a rate lower than the statutory minimum wage (but not less than 50%) unless specifically exempted.

Most workshops populations were employed under the Department of Labor's special exemption certificates at the end of Fiscal Year 1979 (GAO, 1981).

VI. RECOMMENDATIONS

As for most Americans, a major prerequisite to economic self-sufficiency for individuals with disabilities is a job. Employment is an essential key to successful adult integration into community life. Various forms of work are associated with greater independence, productivity, social status, and financial security. Success and quality of life are often measured in terms of paid employment.

Studies indicate that only one-third of youths with disabilities leaving school graduate to a job or some form of advanced education. The absence of a systematic vocational transition process for youths with disabilities significantly contributes to the unemployment rates of persons with disabilities. Of the approximately 12.9 million working age persons reporting a work disability, only 4.2 million (or 32%) were working at the time of the 1980 Census.

Reasons for high unemployment and underemployment among persons with disabilities include the lack of an effective transition process from school to work for youths with disabilities; societal attitudes which cause employers to discriminate against persons with disabilities; physical and communication barriers in buildings, transportation, and worksites; and the lack of appropriate training opportunities for persons with disabilities.

State/Federal vocational rehabilitation agencies, projects with industry, return-to-work programs (established by some businesses), and selective hiring authorities within the Federal Government have increased employment opportunities for persons with disabilities. Although programs such as these encourage education and employment, they are inadequately meeting the goal of successfully integrating persons with disabilities in schools, workplaces, and the community.

To increase employment opportunities for people with disabilities, programmatic changes are needed in several areas.

Transition

1. Congress should direct the Department of Education to designate the State educational agency as the lead agency to start, develop, and carry out the transition planning process.

This nation has invested heavily in special education; to capitalize on this investment, it is necessary for the Federal Government to assure that each youth in a special education program be guaranteed a well-developed, organized and coordinated transition process from school to work.

The regulations accompanying Public Law No. 94-142 should be modified to make the State Education Agency responsible for the transition process. The State and local education agencies should be responsible for initiating and carrying out the transition process, including contacting the appropriate personnel in regular and special education, vocational education, vocational rehabilitation, community colleges, developmental disabilities, and other agencies from whom each student receives services. To support this effort, the regulations should set the following minimum guidelines:

- The planning process is to begin no later than ninth grade, with parents and students actively involved.
- A formal written plan with long- and short-term goals and objectives that include functional skills for employment and daily living is to be prepared and updated annually by the lead agency in consultation with the student, parents, and other involved agencies. Parent and student approval of the plan should be required in writing.

2. Congress should direct the Department of Education to strengthen regulations requiring the involvement of education coordinators and vocational rehabilitation counselors in the transition process.

Vocational rehabilitation counselors and education coordinators (including general, special and vocational education) should be actively involved in the transition process. In addition to prescribing such participation, the regulations should provide minimum standards for the training of vocational rehabilitation counselors and education coordinators in regard to the transition process. Training should focus on strategies for involving employers and families in the transition process, as well as eligibility requirements, and pertinent special education and vocational education techniques. These training requirements, coupled with the State Education Agency taking the lead for transition services (Recommendation #1 above), will establish the foundations for a coordinated transition process. These recommendations can be implemented without additional expenditures of public funds.

Supported Work

3. Congress should amend the Rehabilitation Act to add a title expressly authorizing programs of supported work for persons with severe disabilities who can be competitively employed with the assistance of such a program.

The term "supported employment" means paid employment which (a) is for persons with severe disabilities (such as developmental disabilities, chronic mental illness, and severe physical disabilities) for whom competitive employment at or above the minimum wage without support is unlikely, and who, because of their disabilities, need intensive ongoing support to perform in a work setting; (b) is conducted in a variety of settings, including worksites in which persons without disabilities are employed; and (c) is supported by any actively needed to sustain paid work by persons with disabilities, including supervision, training and transportation.

If supported work programs were available, a large number of severely disabled persons residing in residential facilities could return to the community and become gainfully employed. Some pertinent figures indicate:

- 499,169 persons with mental illness were served in 277 State hospitals for $4.5 billion (Goldman, Gattozzi, and Taube, 1981).
- 243,669 persons with mental retardation were served in 15,633 residential facilities for $5.9 billion (Smith, 1984).
- 1,396,132 elderly and physically disabled persons resided in 23,065 nursing homes (Sirrocco, 1983) and other long-term care facilities at a cost to Medicaid of $12.4 billion (National Study Group on State Medicaid Strategies, 1983).

If permanent authorization and funding for supported work programs were in place under the Rehabilitation Act, these numbers could be significantly reduced. Congress appropriated $3.7 million in Fiscal Year 1985 for grants for supported work programs. Permanent funding is needed to sustain these supported work activities and to develop others.

Funding for supported work programs will provide persons with severe disabilities an opportunity to work toward independence by becoming taxpayers rather than remaining dependent upon other taxpayers. Implementing this recommendation should not entail expenditures of additional public funds. For example, the Medicaid payment process could be modified to allow the funds a disabled person receives while in an institution to follow or accompany the person to the community to pay for educational and vocational services including supported work. Medicaid payments for individuals employed in supported work situations should be much less than if such people remained in institutions. Likewise, the Title XX program funds day activity programs for severely disabled persons not eligible for vocational rehabilitation services. Some portion of funds from that program should be re-directed to provide supported work services for this population, since studies show that many severely handicapped individuals are capable of productive work if given appropriate support services. This change would not involve an increase in funds or an increase in persons served. Rather, day activity programs would simply be encouraged to provide vocational services as part of their programming.

Federal Support For Private Sector Initiatives

4. Congress should extend and expand the Targeted Jobs Tax Credit Program (Deficit Reform Act of 1984).

The Targeted Jobs Tax Credit Program should be made permanent with greater first year tax credit allowances. The TJTC Program should expressly authorize employer tax credits for: reemploying persons who become disabled on the job, hiring disabled persons in higher-than-entry-level positions, and assisting disabled employees who must relocate. Credits should also be allowed for training disabled employees in high demand technical areas.

The existing Targeted Jobs Tax Credit Program gives employers a financial incentive to provide disabled job seekers an opportunity to demonstrate their capabilities. The recommendation to extend and expand this program should result in a net benefit to the Federal Treasury, because the taxes paid by disabled employees assisted by the program should greatly exceed the tax credits allowed to employers. In Fiscal Year 1984, according to the Department of Labor, 38,263 disabled persons were certified under the Targeted Jobs Tax Credit Program.

5. Congress should make Section 190 of the Internal Revenue Code permanent and expand it to a maximum amount of $75,000 per year.

Section 190 encourages accessibility and increases employment opportunities for persons with disabilities by allowing a tax deduction for the removal of architectual barriers. This incentive encourages employers to hire persons with disabilities and elderly people for jobs suited to their needs and talents. Before these individuals can become full working members of society, the workplace must be accessible.

6. Congress should develop innovative and effective incentives to promote the establishment of return-to-work programs.

Incentives should be developed to promote the establishment of return-to-work programs by employers. Return-to-work programs provide early intervention services (counseling, job analysis, etc.) for employees who may become disabled by an injury or illness.

According to Hood and Downs (1985), on-job accidents burdened the 1982 economy with an estimated $31.7 billion in direct and indirect costs. After adding the $24.9 billion cost of off-job accidents (about one third of which was borne by employers), the 1982 total cost was $56.6 billion. During that year an estimated 100 million lost work days resulted from disabling injuries and another 40 million lost days were caused by disabilities from prior years.

Effective return-to-work programs will reduce the cost of health and income maintenance programs by reducing the number of persons with disabilities who are not working. Effective return-to-work programs have been established by businesses such as Minnesota, Mining and Manufacturing Company, Eastman Kodak, and Control Data.

Job Development and Placement

7. Congress should support the development of area model centers on employment for persons with disabilities.

Model centers on employment for persons with disabilities should be established to demonstrate and disseminate information about innovative or "cutting edge" employment strategies. The functions of the centers would include: job analysis; job restructuring; disseminating state-of-the-art information on employment strategies, vocational education, models for coordination of special education, rehabilitation, and vocational education, job development, and placement.

These model centers should be developed through a cooperative effort of the Department of Labor, the National Institute of Handicapped Research, and the Rehabilitation Services Administration (RSA), State and local governments and the private sector, with RSA having the lead role in establishing and operating the centers.

Job Training

8. Congress should amend the Job Training Partnership Act (JTPA) to eliminate the income eligibility requirement for persons with disabilities and to increase the representation of persons with disabilities on Private Industry Councils.

Although the current JTPA legislation helps to increase the employment and decrease the dependency of disabled persons, it has shortcomings. Disabled persons are not being adequately served by JTPA because unlike its predecessor, the Comprehensive Employment and Training Act, JTPA does not consider a person eligible because his/her handicap constitutes a barrier to employment. Income eligibility criteria must be satisfied in order to receive services. In addition, few individuals who understand the needs of persons with disabilities are represented on the Private Industry Councils that direct local JTPA programs. For this legislation to be of substantial benefit to disabled persons, the Department of Labor should ensure that:

- The State Job Training Coordination Councils and the local Private Industry Councils include people who understand the needs, capacities and capabilities of disabled persons, particularly including persons who themselves have disabilities.
- State and local plans have provisions for projects that address the needs of disabled persons.
- Councils place a priority upon and develop methods for achieving the participation of disabled persons in their programs.
- JTPA programs have vocational education and vocational rehabilitation components.
- Parents and educators are informed of the programs available for people with disabilities.
- Data is collected on the number and percentage of disabled persons served.

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TOPIC PAPER C:

DISINCENTIVES TO WORK UNDER SOCIAL SECURITY LAWS

National Council on the Handicapped

February, 1986

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I. INTRODUCTION

In this paper, the National Council on the Handicapped explores the extent to which the income and medical benefit programs authorized under the Social Security Act encourage disabled people to become self-sufficient and gainfully employed. These programs provide many severely disabled people with basic life necessities. However, consumer and service provider experiences indicate that some program provisions encourage dependence and discourage gainful employment. As a result, the Council finds that the multibillion expenditure for these programs is not cost-effective. Over the long run, these program expenditures will be reduced if the programs are modified to reflect the fact that many severely disabled people have the ability to become gainfully employed.

The Council recognizes that disincentives to work result from the combined effect of many policies and programs. However, the Council is focusing this paper on disincentives to work within the Social Security Income (SSI), Social Security Disability Income (SSDI), and related medical benefit programs because of the extent of their influence on disabled people.

II. PROGRAMS FUNDED UNDER THE SOCIAL SECURITY ACT

The Social Security Act authorizes the income support and medical benefit programs which provide the basic necessities of life for many severely disabled people, as well as the only hope for a comparatively independent existence. The following sections briefly describe Social Security Income (SSI) and associated benefits under the Medicaid program, and Social Security Disability Income (SSDI) and associated benefits under the Medicare program.

A. Supplemental Security Income (SSI, Title XVI of the Social Security Act)

Supplemental Security Income is a federally-funded and State-administered program that pays a monthly cash benefit to disabled, blind and elderly persons with limited, intermittant or no work history and limited incomes and assets. Under some conditions, SSI payments are made to disabled children. Persons eligible for SSI benefits are usually referred for Medicaid medical insurance coverage. In 1985, the basic Federal SSI payment for an eligible single adult or child was $325 a month; $488 for an eligible couple. About half of the States supplement this amount (Committee on Ways and Means, 1985, p. 432). In January of 1985, the maximum potential SSI benefits for individuals ranged from $325 to $586 (Alaska); the average yearly SSI benefit in 1984 for an individual was $3,768, or 76% of the poverty threshold (Committee on Ways and Means, 1985, p. 435-446).

Eligibility for SSI disability benefits is dependent upon medical proof of a severe disability expected to last at least 12 months. In Fiscal Year 1984, 2.435 million blind or disabled persons under the age of 65 received SSI benefits. Total Federal Fiscal Year 1984 program costs for the SSI program were $8.5 billion; disabled people represented about 60% of all beneficiaries.

B. Medicaid (Federal-State Medical Assistance Program, Title XIX of the Social Security Act)

Medicaid is a federally funded program of primary and long term medical care for indigent and disabled people. Medicaid pays for health care expenses and other services such as personal care attendants, therapy, and disability-related (prescription) medical supplies.

Medicaid is administered by the States, which have considerable leeway in determining eligibility criteria and benefit levels. States must cover all persons receiving benefits under Title IV-A of the Social Security Act (Aid to Families with Dependent Children, AFDC) and, generally speaking, those who receive SSI benefits. Some States also provide coverage for persons with low incomes who cannot afford medical assistance. Because each participating State has broad flexibility in designing a Medicaid program, the programs differ greatly from State to State.

In Fiscal Year 1986, an estimated $12 billion (of a total estimated Medicaid expenditure of $25 billion) will be expended by the Federal and State Governments in Medicaid payments for disabled and blind individuals. Of this amount, approximately 35% will pay for Intermediate Care Facilities for Mentally Retarded (ICF/MR) persons. Approximately 10% of all Medicaid clients are disabled or blind. (Social Security Bulletin, 1985; Catalog of Federal Domestic Programs, 1985.)

C. Social Security Disability Insurance (SSDI, Title II of the Social Security Act)

The Social Security Administration provides monthly disability income benefits to workers who meet the insured status requirement (work at a certain level for a specified number of years) and who are determined to be disabled. Disability benefits may also be paid to a disabled adult (over age 18), children of a deceased, disabled, or retired eligible worker, and to disabled widows (of formerly eligible workers) who are over the age of 50 and who meet specific medical standards.

Earned work credits are used to determine whether an individual meets the status requirement. The credits vary according to the person's age before onset of the disabling condition. In general, workers over the age of 30 need at least 5 years of work credits in the 10 years immediately before onset of disability in order to be eligible for SSDI benefits. SSDI benefit payments are based on the worker's lifetime average earnings that were covered by Social Security.

SSDI benefits are paid from a special trust fund that is financed by Social Security taxes. Eligibility for SSDI payments requires proof that the individual is unable "to engage in any substantial gainful activities by reason of a medically determinable physical or mental impairment which has lasted or can be expected to last for 12 months or to result in death."

Section 202(d) of the Social Security Act requires that all applicants for, and recipients of, SSDI benefit programs be referred to the State vocational rehabilitation agency if they are considered likely to benefit from services. The screening process is based on criteria established jointly by Vocational Rehabilitation and Social Security.

Although the disincentives to employment described below may affect the success of the Beneficiary Rehabilitation Program (BRP), no one knows what percentage of SSDI recipients would actually become employed under an "ideal" system. However, a study conducted by Rutgers of 1973 beneficiaries found that employment rates were highest among comparatively well educated, young male recipients of benefits (Berkowitz, 1980). Current statistics provide a limited perspective on prospects for employment among SSDI beneficiaries: In 1982, 47% of disabled SSDI beneficiaries were over age 54 (as compared to 32% of the adult

U.S. population), and 27% had less than a high school education (as compared to 19% of the adult U.S. population). Circulatory, skeletal-musculo and neoplasms accounted for 58% of the disabling conditions; 81% of SSDI recipients were ambulatory outside of the house without assistance. (Committee on Ways and Means, 1985, p. 113-115.)

The average monthly SSDI income benefit for a disabled worker in early 1985 was $449; the average payment to a worker with a family was $893. In 1984, 2.6 million workers received benefits, or about 3.4 persons per 1,000 employed workers. The addition of dependents brings the total number receiving SSDI benefits to 3.8 million. Approximately $18.1 billion in benefits were paid out in Fiscal Year 1985. (Social Security Reference Guide, 1985.)

D. Medicare (Title XVIII of the Social Security Act)

Disabled workers who are eligible for SSDI receive Medicare hospital insurance after they have been entitled to monthly disability checks for 24 months. Medicare assists in the payment of inpatient hospital care and certain types of short term follow up care, including short term home health aides and homemaker services. An additional, voluntarily obtained Medicare program pays the costs of physician services and other medical items not covered under the Medicare Hospital Insurance program. The monthly cost in 1985 for this coverage is $15.50. Individuals who require on going medical supplies and personal care assistance obtain services under Medicaid after qualifying through "spend down" procedures: applicants must document that their medical expenses reduce their monthly income below the Medicaid eligibility income ($370 in 1985) over a six month period.

In 1984, almost 2.9 million disabled persons received Medicare hospital (Part A) insurance protection at an annual benefit payment per disabled person of

$1,643. Benefits were used by 770,000 beneficiaries. Part B supplemental coverage was purchased by 2.66 million disabled beneficiaries; 1.9 million persons received an average reimbursment of $1,545 for medical services obtained under Part B. (Ways and Means Committee, 1985, p. 123.)

III. DISINCENTIVES TO WORK

Although Congress has changed the Social Security legislation to reduce disincentives to work, disincentives remain in the program. This section discusses the nature of these disincentives and briefly identifies other constraints on the ability of a disabled person to obtain employment.

A. Eligibility for the SSI and SSDI Programs is Based on Inability to Work

By definition, eligibility for SSI disability benefits or SSDI benefits is based on the assumption that disabled beneficiaries are unable to work. In principle, a person who is able to work should not be entitled to disability benefits.

However, disabilities obviously cannot be categorized simply as those that prevent one from working and those that do not. Many persons with severe medical impairments are able to accept some type of employment. For example, a person with a spinal cord injury might be able to work full time for several years following rehabilitation after the onset of injury until disability-related medical problems force him or her to stop. Another person with a similar disability might be able to work twenty hours a week for many years; another might not be able to work at all. Similar differences occur among persons with developmental disabilities, particularly if individuals have multiple disabilities.

Currently, individuals with certain specified medical diagnoses (e.g., deafness, blindness, quadriplegia) are automatically considered eligible for SSI and SSDI disability income benefits unless they have a substantial work history after the onset of disability. For those without such clear medical diagnoses (e.g., persons with severe back pain, some types of cancer and mental illness), the deciding criteria becomes the duration of disability (at least 12 months duration) and the inability to work. In some instances as much as a year's time may elapse if an individual and his or her lawyer and family contest the disability determination findings. The emphasis on inability to work in the application process can have destructive effects on the applicant's morale and willingness to try to return to work.

The automatic assumption that a person with a severe disablity cannot work also creates problems. In particular, automatically providing income benefit payments to a severely disabled young person who could develop work skills can destroy the incentive to become self-sufficient. For this reason, some disabled individuals argue against automatic eligibilty for SSDI and SSI benefits on the basis of disability.

Ability to work is dependent upon a large number of variables, including training, dexterity, physical strength, attitudes and competencies, and economic conditions. In fact, many severely disabled people have both the ability and the desire to work, but face substantial barriers to employment. This is particularly true for an individual who cannot earn enough to cover the cost of high disability-related expenses that are covered as part of their eligibility for SSI or SSDI. Such individuals cannot afford to lose the medical benefits associated with income support payments--they literally cannot afford to work. However, employment is an essential key to successful adult integration into community life. Various forms of work are associated with greater independence, productivity, self-esteem, social status and financial security. Success and quality of life are often measured in terms of paid employment, and work is an important component of each individual's right and obligation to live as independently and as responsibly as possible in the community. Defining disability as the inability to work denies disabled individuals the opportunity to reach their full potential as contributing members of society.

B. A SSI or SSDI Recipient Who Returns to Work Usually Faces a Reduction if Not Loss of Income and Benefits

Many disabled people want to work but cannot risk losing their medical benefits. Some disabled persons, such as spinal cord injured individuals, require disability-related medication, supplies, personal care attendant services, and equipment throughout their lifetimes. Often these expenses cannot be paid by a disabled person with the typically low income associated with most entry level jobs. In addition, few private insurers offer medical insurance coverage for preexisting conditions.

The potential loss of employment threatens the hard-won independent lifestyle of many of these individuals. Their work choices are more limited than those available to their nondisabled counterparts, so a job loss often means long periods of unemployment. Furthermore, reentry into income support programs is often arduous and time consuming, a threatening prospect for an individual with extensive requirements for ongoing medical services. For these reasons, employment may not be a cost-effective option for some disabled individuals if it means the loss of medical benefits.

However, there is some evidence that employment helps individuals stay well. The Allied Health Program at Boston University recently compared the health of employed and unemployed persons with severe disabilities (Conversation with Project Analyst, 7/8/84). Their findings support the statement that, in general, disabled people who are employed require medical attention less frequently than unemployed individuals.

The total benefit and income loss or gain must be considered when a disabled person who receives public benefits goes to work, including the loss of income support, medical care coverage, and social services. The potential income loss is particularly striking in the SSDI program. Beneficiaries who returned to work in 1984 and earned the substantial gainful activity (SGA) wage of $300 per month or more--about three-fifths of the minimum wage for a full-time worker--were allowed a nine month trial work period if they returned to work. At the end of the trial work period, they were re-evaluated. If thought capable of earning over $300 per month, the individual was terminated from SSDI. However, there is little incentive for a SSDI recipient to work for a salary of $300 per month. Total benefits are usually higher than $300 per month, especially when the individual has dependents or has high disability-related medical and transportation costs.

Continuation of health benefits may be as important to a disabled person as income support payments, especially if ongoing medical services, supplies and personal care attendant services are needed. Prior to 1981, SSDI beneficiaries who lost their entitlement to cash benefits also lost their entitlement to Medicare. Beginning in 1981, however, Congress changed the law so that SSDI beneficiaries who lose their entitlement to cash benefits can continue to be eligible for Medicare or Medicaid (spend down) benefits for 36 months. Because of the three year time limit on this provision, and the difficulty of obtaining private health insurance coverage, this provision reduces but does not eliminate this source of work disincentive.

Also in 1981, Congress attempted to eliminate some of the major disincentives from the SSI program through the Section 1619 demonstration program. Section 1619(a) authorizes special cash benefits as long as the SSI recipient's earnings are below the Federal break even point--$735 for an individual in 1985. The other special demonstration, incorporated as Section 1619(b) of the Social Security Act, continues Medicaid coverage for SSI recipients who return to work. Coverage can continue even if cash benefits terminate when earnings exceed the Federal breakeven point, provided that the recipients 1) continue to qualify on the basis of limited assets, 2) would not be able to pay for medical benefits equivalent to Medicaid, and 3) would have difficulty maintaining their employment without such coverage.

These demonstrations have been underutilized, however, because until recently little information about the demonstration was disseminated to recipients and Social Security personnel, and partly because the program is very complex. According to Patricia Owens, the Associate Commissioner for Disability in the Social Security Administration (1985), in August of 1984 just 406 individuals received Medicaid coverage through the special cash benefits provision of Section 1619. Another 6,804 individuals retained their Medicaid eligibility although they received no cash benefits. The average earnings of recipients of the special cash benefit were $464 per month, allowing an average Federal monthly payment of $127. The average earnings of Section 1619 participants who retained only Medicaid were $666 per month.

The Social Security Disability Reform Act of 1984 (Public Law 98-460) extends Section 1619 (a) and (b) to 1987. It also requires the Secretaries of the Department of Health and Human Services and the Department of Education to train their own staff and to inform SSI applicants, recipients and concerned public and private agencies and organizations about the provisions of Section 1619.

By mid-1986, data is to be collected by the Social Security Administration and the Health Care Financing Administration about the characteristics of the individuals benefiting from Section 1619, the effects on work efforts and the types of health care services utilized and their costs.

The reduction of income and the loss of health benefits remains a problem, however, because of the temporary and time-limited nature of Section 1619. SSDI beneficiaries currently have no similar income protection, and their medical benefits are currently limited to three years after the onset of gainful employment. The problem is severe because few employers provide health insurance coverage for preexisting conditions, and many employers provide no health insurance coverage at all.

C. Private Health Insurance Is Not Available to Many People with Disabilities

Some disabled workers are forced into income support programs primarily because they cannot obtain private medical insurance coverage because of preexisting conditions. Persons with disabilities who are self-employed often have great difficulty becuase they rarely have access to a group insurance program. Furthermore, many small businesses that offer the low paying jobs held by many people with disabilities offer no medical coverage at all. For instance, in recent testimony (1985) before Congress, William H. Ashe, the Director of an Adult Developmental Disabilities Program in Barre, Vermont, reported that of 67 different paying positions held by disabled individuals in his program, only 19% offered Medical benefits, and only 10% full benefits. This experience is not unique to Vermont.

Eight States, including Wisconsin and Connecticut, currently sponsor high risk medical insurance pools for individuals who cannot otherwize obtain medical insurance. However, these pools are costly and provide protection primarily against catastrophic illnesses.

Consider the costs of insurance with different deductibles under Connecticut's high risk pool (data provided by Jack Hoadley, Legislative Assistant to U.S. Rep. B. Kennelly, 11/04/1985):

Age & Sex Category	Annual Deductible	Quarterly Premium	Maximum Annual Cost
Male, >age 30	$1500	$ 90.84	$1863.36
Female, age 50	$1000	$376.00	$2504.00
Female, age 50	$1500	$293.00	$2672.00
Female, age 60	$ 400	$800.00	$3600.00
Female, age 60	$1500	$450.00	$3300.00

The maximum annual cost includes the deductible and four quarterly premiums. In general, the pools do not cover persons over age 65, since they are usually eligible for Medicare. These data indicate that the risk pool does not provide a realistic alternative for individuals with low incomes or those with medium incomes who have high disability-related work expenses. The high risk pool, when available, does meet the medical insurance needs of individuals with comparatively high incomes. State government support for the development of such pools suggests that States might lead the way in the development of cost-effective methods of meeting the health insurance needs of uninsured disabled persons with low incomes. Federal incentives (or demonstration funds) could stimulate more innovation at the State level.

To support the independence and self-sufficiency of persons with disability, health insurance should provide the coverage for the following services:

- In-home and community-based care (and avoid insitutional care)
- Preventive care, including early intervention and the prevention of secondary disabilities
- Rehabilitation services to support return to work and maximum independence
- "Wrap-around" coverage for eligible persons with inadequate health insurance coverage.

D. The SSI or SSDI recipient Who Returns to Work Loses the Income Security Associated with SSI and SSDI

Both disabled and nondisabled people are often as much concerned about the security of their income as they are about the amount. They will sometimes forego higher paying jobs in favor of those that are protected by seniority, tenure, civil service or other means. Beneficiaries of public support often have little incentive to exchange a secure source of monthly income for employment that reduces or adds little to net income.

Congress attempted to reduce the fear of loss of income security by providing a 15 month reentitlement period following the trial work period for both SSDI and SSI beneficiaries. However, this does not resolve the problem because severely disabled people often face an unreceptive job market. In general, people with disabilities receive lower pay and experience more difficulty in locating jobs than their nondisabled counterparts. As a result, they experience more intermittant and underemployment than the general population.

E. Other Related Problems that Discourage SSI and SSDI Recipients from Working

The issues described below are treated in more detail by other Topic Papers prepared by the Council. They are included here because they greatly affect the ability of disabled people to work independently within their communities.

1. The Public and Private Sectors Offer Limited Employment Opportunities to Disabled People. Employer attitudes keep many disabled people out of the workforce. Many employers will not hire someone with a medical history of cancer or a disability regardless of their current medical condition. Modifications, such as adding a ramp and minor modifications to make an accessible work station for a physically disabled individual, or simplifying a task to make it consistent with the abilities of a developmentally disabled individual, requires an effort that frequently is not made.

2. Absence of a Continuum of Vocational Services. In most States the State rehabilitation agency is limited to providing initial, short-term funding for employment-related services. This service usually includes case management. In general, there is no Federal source of funding for long term or intermittent vocational services other than sheltered workshops. As a result, such services often are not available in many communities.

The lack of cross-agency coordination in some States and communities further complicates the problem. For instance, on occasion a person is determined ineligible for SSI or SSDI benefits because he or she does not meet the standards for disability payments and is simultaneously found ineligible for vocational rehabilitation services because there is little or no reasonable expectation that employment would result from receiving services. In some States sheltered employment is an option; in others, the individual may completely "fall through the cracks."

3. Low Cost Accessible Transportation is Not Available in Some Communities; Accessible Vocational and Medical Special Transportation Services Often Stop when Other Benefits Cease. Severely disabled people may lack the transportation they need to move into the integrated competitive market place. If public transportation is available and accessible, it meets this need. However, if accessible public transportation is not available to the work site, the cost of other transportation may remove low paying jobs from consideration. State agencies (vocational rehabilitation, mental retardation and developmentally disabled) usually pay for or provide special transporation for their clients during the time they are receiving services, but this assistance stops when the client enters unsupported competitive employment. In a limited but unknown number of communities, other funding sources provide some transportation assistance.

4. An SSI or SSDI Recipient who Returns to Work Often Loses Access to Supported or Accessible Living Arrangements. The absence of affordable, accessible housing and alternative housing arrangements (group homes, supervised apartments) in many communities presents an insurmountable barrier to many disabled people. In some instances individuals who earn above certain limits lose their eligibility to live in a group home. The problem is acute because accessible housing is often unavailable at the cost and level of accessibility and supervision needed (NADCC, 1985, p. 43-44). Physically disabled persons often have great difficulty locating affordable, accessible housing, since nearly all such housing is located in federally subsidized Section 8 housing, which

requires a means test for occupancy.

IV. CASE STUDIES

Three case studies are presented below. Two are success stories associated with Section 1619; the other demonstrates the work disincentive that results when a person with severe disabilities who has vocational potential but no work experience is automatically eligible for income support payments.

A. John M.

John M. is a 35 year old man with a spinal cord injury due to an accident three years ago. He was divorced at the time of the accident; he is the father of two young children. John was employed before he became disabled as a skilled construction worker with an average yearly income of $30,000. He has a high school diploma and a vocational training program certificate in electrical and welding skills.

Today, John is physically dependent in all of his activities of daily living (e.g., cooking, housekeeping, shopping, and personal care needs such as bathing, grooming, and dressing). He uses an electric wheel chair and recently acquired a modified van with the assistance of vocational rehabilitation. John takes medication on a daily basis and requires ongoing medical supplies. To assist him with his every day personal care, John requires the services of personal attendants.

During his stay at City Rehabilitation Hospital in 1982, John was referred to the Massachusetts Bureau of Vocational Rehabilitation. His counselor arranged an assessment of John's functional and intellectional abilities and counseling in career goals. John had a strong desire to return to work, and his aptitude testing indicated that he would be a good candidate for computer training. With vocational rehabilitation funding, John attended a two year college and received an Associate of Arts degree in computer programming. Shortly before his graduation, John received several offers from potential employers. Initially, John did not accept employment because he did not want to lose his medical benefits. However, his vocational rehabilitation counselor referred him to the Social Security Office and he obtained Section 1619 coverage. He then accepted employment because he could retain Medicaid coverage for his attendant care and other disability-related medical needs.

Currently John is employed at the Metropolitan Insurance Company as an entry level computer programmer. His employer installed a ramp and modified a work station to accommodate John's wheel chair. He has entered a Bachelor of Science program at a State university where he will study computer analysis. John is funding his continuing education with Metropolitan's employee benefit program and student loans.

Prior to employment, John received SSDI income benefits of approximately $600 per month and, through a "spend down," became a recipient of Medicaid. Now that he is working, John no longer receives SSDI income--instead, he pays taxes and contributes to the local economy. Under Section 1619, John continues to receive Medicaid benefits for disability-related expenses.

B. Rachel S.

Rachel S. is a 50-year-old woman who is multiply-disabled due to cerebral palsy and mental retardation. Rachel had been placed in a State institution at the age of five when her parents could no longer care for her; she has no functional math or reading skills. Five years ago, Rachael told her Department of Mental Health service coordinator that she wanted to leave the institution. Her service coordinator referred her to her local independent living center. There Rachel received independent living skills training and participated in a transitional living program for three years before moving into an independent living arrangement in her community.

Rachel is physically dependent on assistance for all of her daily living and personal care needs and uses a wheelchair for mobility. She receives support in managing her finances and some other aspects of her personal life from an environmental support specialist provided by the Department of Mental Health.

Currently Rachel is employed in a supported work program. She shares an apartment with her roommate, Peggy, who has a similar background. Their skills are complementary; each helps the other to live independently in the community. Rachel receives Medicaid benefits through Section 1619 that pay her attendant care and disability-related medical needs.

The cost of institutional care for Rachel came to approximately $60,000 per year. She now earns about $3.50 per hour for an annual income of $7,000. Her medical benefits (approximately $5,200), environmental support specialist assistance ($364), and housing subsidy ($7,121) total about $12,685 per year. This represents a savings of $47,315 over the cost of maintaining Rachel in an institution. In addition, Rachel now pays taxes and contributes in other ways to the local economy.

Rachel is successfully integrated into her community. She serves as a member of the Human Rights Council at the Department of Mental Health. Since becoming independent, a test of intelligence showed that Rachel had gained 10 points. Best of all, Rachel states that she has a much happier life today.

C. Laura

Laura is a beautiful 15-year-old who has been deaf since birth. For the first five years of her education, she attended a State school for the deaf. At ten, she was "mainstreamed" into a community school and provided with a full-time interpreter who accompanied her to all classes and school events. So far, the message from her government is: with a good education, you can become self-supporting. The funds we invest in your education will save large sums of money since we will not have to support you for life. In large part, due to the integration and interpreting support, Laura did well in school. She was on her way.

At 14, Laura became eligible for Supplemental Security Income because she was deaf. Checks began arriving at her home monthly and Medicaid paid for much of her medical care. The government now sent Laura this message: you are entitled to government aid.

For Laura, the checks seemed inordinately large. Because she did not have to pay for her housing, transportation, food or other daily living expenses, the subsidy was in fact a large one. At first, there was little effect on Laura or her family. Soon, however, both she and her divorced mother (who received Aid to Families with Dependent Children payments) began to depend upon the monthly checks.

Within six months, Laura had changed. She was absent from school more often. Her grades slipped precariously and she was placed on academic probation. In the classroom, she often engaged her interpreter during class lectures in private, signed conversations about boys, clothes, and makeup. Within one year, she had become a "D" student with no motivation even to complete high school. She no longer talked about going to college and becoming a teacher. As Laura told her interpreter one day at lunch: "Why study? I'm set for life."

Maintaining Laura on unneeded, dependency-creating disability income payments throughout her lifetime will cost this nation's tax payers many thousands of dollars and will yield no return on our investment in her education.

V. COSTS AND BENEFITS

The case studies in the previous section suggest that considerable savings can be realized by removing the disincentives to work in current programs. Although there is no accurate method of estimating costs and benefits associated with the permanent extension of Section 1619, the Congressional Budget Office has informally estimated that no increases in costs are associated with its permanent extension.

Others have projected considerable cost savings. For instance, in August of 1984, 6,000 SSI recipients earned over $713 a month, the break even point for going off of SSI payments. If permanent, continued Medicaid coverage encouraged these individuals to leave the SSI program, a savings of $324 a month per individual in SSI payments would result, or a projected reduction in cash benefits of $23 million per year (Bartlett, 1985).

The Adult Developmental Disablities Program in Vermont (Ashe, 1985) reports employment experiences that support these estimates:

> Since April of 1980, we have assisted 46 different individuals in becoming employed. Had these persons participated in the day treatment center which was available to them at the rate of $20 per day, rather than working in a competitive job, it would have cost $330,890 in Medicaid reimbursements. That figure in and of itself is nearly equal to the total cost of the job placement program which assisted them in becoming employed. In addition to this obvious benefit, the cash payment portion of these worker's SSI benefits have been reduced by $31,577 as a result of this increased earning power. Beyond these direct savings, however, these individuals have been offered the opportunity to participate fully in our economy, rather than continuing to depend on that economy because of the participation of others. In fact, these 46 persons have earned within the competitive job market $288,757 in wages, and have contributed taxes from these earnings in the amount of $32,977. Without question, these persons have moved from a position of nearly total dependency on government-sponsored programs to one of being largely independent of government for their existence.

In a 1985 study, a Napa/Sonoma California SSI/SSDI Task Force calculated estimated savings in income cash benefits had Section 1619(a) & (b) been in place in a local workshop for the last 10 years. The Task Force found that:

> Prior to the existence of Section 1619, individuals working in sheltered workshops and work activity centers often quit their employment when they received notice from Social Security that they would lose their cash and medical benefits due to their earnings from working. In 1979, individuals with IQ's of 69 or less and persons diagnosed with chronic schizophrenia were understandably frightened when their $379 monthly SSI cash and medical benefits were threatened by workshop earnings of $280. One has to be extremely handicapped not to realize that $379 with medical benefits is better than $280 with no medical beneifts. Since 1975, and prior to the existence of 1619(a)&(b) in 1980, a work activity center examined by the Task Force Committee had 25 SSI recipients quit employment rather than lose their SSI benefits. If they had remained in the work activity center, Social Security cash benefits would have been reduced by a very conservative $300,000 over ten years (i.e., $100 reduction x 25 individuals x 12 months x 10 years).

Assuming that 1,000 work activity centers experienced a similar situation, a savings to the taxpayers of $300 million over a 10 year period would result. The Task Force examined a work activity center that employs 180 severely and permanently disabled individuals. In the last six months, four of these individuals quit work or cut back the number of hours they worked in order to earn less than $300 a month and retain their SSDI. In the Committee's opinion, if they received vocational training many of these individuals should be capable of earning more than $300 a month. However, $300 would not be enough to meet their medical and living expenses.

As part of the same study, the Task Force obtained data on the effectiveness of Section 1619 from Napa Valley P.S.I., Inc. PSI is a work activity center located in Napa, California. In January of 1985, PSI saved the Social Security Administration $8,362 over a five week period. It did so by providing work (resulting in paid income) to 163 severely and permanently disabled individuals who earned enough to reduce their SSI benefit payments by $8,362 over a five week period. The Task Force calculated that these savings would result in an annual savings to SSI of $86,965, as follows: $8,362/5 wks. = $1,672/wk x 52 wks = $86,965.

The Task Force projected these savings on a national scale by estimating the savings if each of the 225,017 disabled workers in the 4,814 work activity centers and workshops certified by the Department of Labor in September, 1984 showed similar savings. The average savings per individual in the PSI workshop is $534 ($86,965/163 disabled workers). National savings on an annual basis would be $120 million ($534 x 225,017 disabled workers). This, the Task Force submits, represents a substantial savings.

Savings to the government can result from innovative methods under current programs. The Chapter 599 program in Massachusetts makes special status Medicaid benefits available to severely disabled people who could not afford to work without medical benefits. Based on its follow-up of 91 clients, the Massachusetts Rehabilitation Commission (personal communication with analyst, July, 1985) calculates that it saved taxpayers $408,670 in 1984, calculated as follows:

Income Taxes Paid:	Federal	$134,000
	State	58,000
SSI Payments not made		33,670
Client contributions on a sliding scale for attendant services		143,000
	Total Saved	$408,670

The benefits to society are even greater if individual benefits, such as increases in self-esteem and mental and physical health, and economic benefits to the community such as purchase of goods and services are considered. Assuming that comparable numbers of SSI beneficiaries would be encouraged to work in every

State, 4,732 individuals (52 States x 91 persons) would benefit from the permanent extension of Section 1619 for a national savings of approximately $21.25 million (52 x $408,670).

VI. RECOMMENDATIONS

The income and medical benefit programs authorized under the Social Security Act provide many severely disabled people with basic life necessities. However, some Federal programs under current Social Security laws not only fail to promote employment and independence for citizens with disabilities, but actually penalize and discourage people with disabilities if they become employed. The Council believes that the multibillion dollar expenditure for these programs--Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), Medicaid and Medicare--would be reduced if the programs were modified to reflect the ability of many severely disabled people to become gainfully employed. The programs should assure that people with disabilities who work have access to medical insurance and that individuals who begin working while receiving benefits from Federal income support programs increase their income.

Currently the Social Security Administration's (SSA) process for determining eligibility for SSI or SSDI income benefits begins with a medical evaluation of the individual's disability. Only in cases in which the disabilty is not on the SSA "medical list" (e.g. blindness, deafness, spinal cord injuries) does the eligibility determination include both a medical diagnosis and an assessment of vocational potential. This determination process can sometimes result in the automatic award of benefits to individuals with clearly defined medical disabilities who have significant vocational potential and should be able to work. A major disincentive to work for many current SSI and SSDI recipients is that employment in many entry level and low paying service jobs will often result in reduced income and the loss of medical and other benefits. The Council also finds evidence that many people with preexisting medical conditions cannot obtain adequate health insurance at an affordable cost. This problem creates an incentive to enter public aid programs since the medical costs associated with some disabling and preexisting conditions exceed the working individual's ability to pay.

1: Congress should amend the Social Security Act to make eligibility for SSI and SSDI programs dependent upon the presence of a severe medical disability and a functional assessment to determine vocational potential whenever deemed appropriate.

Whenever the vocational potential of a working age applicant is at issue, applicants who are not terminally ill should be required to undergo a functional vocational assessment that establishes that they will have substantial difficulty working because of severe vocational limitations of an ongoing nature. Individuals with disabilities who are refused SSI and SSDI income support benefits because they are determined to be able to work should be offered vocational rehabilitation services.

This recommendation is designed to change the focus of disability determination from a purely medical standard to one that assesses the full range of factors that affect the ability to work of persons with disabilities. It narrows the definition prevent those who have a medical impairment but the ability to work from automatical becoming eligible for income support benefits.

To implement this recommendation, the Social Security Administration should be charged with developing procedures for conducting functional vocational assessments and for assuring that adequately trained people are available to carry out the assessments. For instance, SSA could contract for this service with independent agencies, such as independent living centers, vocational rehabilitation agencies, or colleges and universities. SSA should also enter into cooperative agreements with State vocational rehabilitation agencies to assure that individuals who are refused benefits because of their vocational potential are not then refused vocational rehabilitation services. Applicants should not be required to undergo a second, duplicative vocational assessment if they are referred to vocational rehabilitation for services.

2. Congress should amend the Social Security Act to assure that SSI and SSDI recipients who become gainfully employed are permitted to retain benefits and have access to medical insurance in circumstances where the loss of such benefits would substantially negate the income they might earn.

Three steps should be taken to implement this recommendation. First, Section 1619(a)&(b) of the Social Security Act, which authorizes continuing cash benefits and Medicaid coverage to working SSI beneficiaries, should be made permanent, thereby removing the uncertainty associated with the temporary nature of Section 1619.

Second, Section 1619 provisions should be extended to SSDI recipients. The formula for determining benefits when earnings increase may need to be modified since some SSDI recipients receive comparatively high benefit payments. If the same Federal break-even point used for SSI were used for SSDI, benefits might reach inappropriately high levels.

Third, Medicare and Medicaid coverage should be made available on a sliding fee scale that reflects income to working SSDI and SSI beneficiaries who cannot obtain private health insurance coverage because of their disabilities. Employers should be required to contribute an amount equal to that contributed to other employee health insurance plans. Alternatively, cooperative programs with insurance programs might be developed in which Medicaid pays disability-related medical expenses and the private insurer would be responsible for other medical expenses.

3. Congress should direct the Health Care Financing Administration to study and recommend cost-effective methods for providing health insurance coverage to persons with preexisting conditions who cannot obtain adequate health insurance coverage from private insurers at affordable rates. The study should be conducted in consultation with the National Council on the Handicapped and findings and recommendations should be reported in hearings before Congress within two years of the date of enactment of this provision.

Some disabled workers are forced into income support programs primarily because they cannot obtain private medical insurance coverage due to the preexisting conditions of diabilitiy. Persons with disabilities who are self-employed often have great difficulty because they rarely have access to a group insurance program. If a disabled worker's income is not sufficient to cover both basic living and medical expenses, the worker may be forced into a public assistance program in order to obtain the needed medical benefits.

The Council believes that the availability of health insurance coverage for people with disabilities is an important incentive to employment, and that the States may be able to provide leadership in this area. Innovative programs in place in those States that provide health insurance coverage for uninsured populations should be examined, and a variety of funding and insurance strategies should be considered.

Considerable savings can be realized by removing the disincentives to work in current programs: Medicaid benefit payments often decrease when a person with a disability is employed. Income support payments will always be reduced as recipients of income benefits become gainfullly employed and income support benefits are reduced or ended. Although there is no precise method of estimating costs and benefits, the Congressional Budget Office has informally estimated that no increases in costs are associated with a permanent extension of Section 1619. Other authorities have projected considerable cost savings. For instance, in August of 1984, 6,000 SSI recipients earned over $713 a month, the break-even point for going off SSI payments. If permanent, continued Medicaid coverage encouraged these individuals to leave the SSI program, a savings of $324 a month per individual in SSI payments would result in a projected reduction in cash benefits of $23 million per year (Bartlett, 1985). The advantages to society are even greater if individual benefits, such as increases to self-esteem and mental and physical health, and economic benefits to the community, such as the purchase of goods and services, are considered.

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TOPIC PAPER D:

PREVENTION OF DISABILITIES

National Council on the Handicapped

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I. INTRODUCTION: PREVENTION OF DISABILITIES, THE PROBLEM AND THE PROMISE

The National Council on the Handicapped has identified Prevention of Disabilities as a major priority for action by the Congress. Preventive action can greatly reduce the human suffering and costly and time-consuming interventions associated with disability. The estimated 35 million Americans with disabilities were victims of disease, accidents and/or lifestyle practices which affect health. A number of studies indicate that many of the causes of disability are preventable. Preventive action can greatly reduce the number of Americans who develop disabilities each year and the severity or multiplicity among persons with preexisting disabilities.

It is estimated that the United States spends more than $400 billion in health care, mostly for primary treatment of disease and injuries. Less than 5% of the Federal health dollar is allocated to disease and injury prevention and health promotion. Unfortunately, the absence of preventive action costs our nation billions in health care and many unnecessary deaths and disabilities at a time when there is a recognized and urgent need for cost containment of health care.

Although there has been progress in disease and accident prevention and health promotion, much more can and should be accomplished. Our nation has the knowledge, technology and resources needed to mount an effective and successful national disability prevention program. For example, infant mortality rates have realized a rapid decline. In 1965, the mortality rate was 25 deaths per 1,000 live births; in 1983, the rate was 10.9 infant deaths per 1,000 live births (National Center for Health Statistics, 1984). Even with the reported decline in infant mortality, 42,000 babies die before their first birthday and 250,000 are born with serious birth defects or illnesses--many of the deaths and potential disabilities could easily be prevented. While adequate prenatal care can be provided for as little as $250 to $350 per patient, the average national cost of caring for a premature child is $20,000 to $40,000 per child during infancy; the cost of institutional care for a child born mentally retarded is estimated at $20,000 to $30,000 per year with a lifetime average cost of between $500,000 and $1 million.

Another tragic example of our nation's lack of focus on prevention is the needless number of deaths and disabilities resulting from auto accidents. In 1982, 35,512 persons were killed in motor vehicle accidents. However 2,490,000 persons were injured with more than 170,000 sustaining severe and disabling injuries to the head and brain (33%), spinal column (5.0%), chest (27.7%), abdomen (22.4%), and arm and legs (11.9%) (National Highway Traffic Safety Administration, 1984). Despite the improvement in the crashworthiness of motor vehicles, the reduction in speed limits, and the encouragement of seat belt usage, we are still realizing far too many deaths and disabilities from such accidents. If there were a 70% seat belt usage rate in the United States, it is estimated that 9,140 lives will be saved and 327,000 injuries reduced or prevented (U.S. Department of Transportation, 1984).

Other areas of prevention which need attention include disabilities due to heart disease and stroke; occupational accidents and hazards; home, recreational and pedestrian accidents; genetic disorders; infectious diseases; chronic diseases; toxic substances in the environment; noise pollution; radiation; and gunshot wounds. Finally, there is need to encourage Americans to use healthy lifestyle behaviors. These include nonsmoking and restricted use of alcohol, increased exercise and weight control, improved diet and nutrition, control of stress, periodic medical examination and tests, and safety precautions. In 1984, Louis Harris and Associates conducted a survey on preventive behaviors of Americans. Thirty percent of American adults practice more than 75% of "good" lifestyle habits; 50% of adults practice 51-75% of the desirable habits; and finally, 10% practice 50% or fewer of the habits (Young, 1985, p. 8). As expected, the people most likely to engage in health-promoting behavior have incomes over $25,000, are college-educated and currently in good health and think they have a great deal of control over their future health. The challenge is to reach all Americans, with a special emphasis on encouraging young persons to practice these favorable behaviors.

The National Council on the Handicapped recommends that the Federal Government mount a national program for the Prevention of Disability by coordinating the prevention efforts of existing Federal programs, by providing additional resources for expanding prevention-related activities, by introducing new legislation to accelerate development of prevention-related activities at the State and local levels, and by providing national leadership to encourage the application of community-based, coordinated, systematic programs of prevention throughout the United States. A study of the feasibility of community-based models for prevention has concluded that the greater portion of the necessary resources needed for an effective prevention program is already available in most communities (Marge, 1981). The Federal Government, therefore, should focus on providing leadership and coordinating Federal programs. Limited additional funds should be provided to support a modest expansion of current programs and to stimulate community-based prevention efforts.

II. DEFINITIONS

Disability prevention attempts to eliminate or reduce those factors which result in disability. This is contrasted to acute and long-term health care which intervenes after an individual develops a disorder. The progression from cause to disability is reflected in three levels in the definition of prevention, as follows.

Primary Prevention refers to the elimination or inhibition of factors that lead to the onset and development of a disorder. Primary prevention recognizes that individuals differ in their susceptibility to causes of disease or injury. In such cases, primary prevention attempts to reduce exposure of all "at risk" individuals to causes that result in disability. Examples of primary prevention strategies include immunizations, sanitation efforts, purification of water, public education about disease and injury prevention and health promotion, the use of auto safety belts, and recommended diet, exercise and weight control to prevent cardiovascular disease and stroke.

Secondary Prevention refers to the early detection and treatment of disorders in their beginning stages, especially before they create permanent disabilities. The major strategy of secondary prevention is screening persons with symptoms of a disorder and persons without symptoms but who are at risk in the population. Examples of secondary prevention strategies include hearing screenings at birth and throughout life, periodic vision screening, cancer screening programs for individuals over the age of 50, early childhood intervention programs for at risk infants and young children, and hypertension screening programs for at risk persons (smokers, drinkers, obese and sedate individuals, persons age 40 and over, persons with history of hypertension and persons under great stress).

Tertiary Prevention refers to the reduction of a disability by habilitative and rehabilitative methods to restore as much effective functioning as possible. At this stage in the progression of a disorder, the person is disabled and in need of specialized services. The person who is quadriplegic as a result of an auto accident or who is legally blind as a result of glaucoma will need special services in order to be effective socially and vocationally. Also, tertiary prevention helps reduce the development of more severe disability, including additional or related disorders. Examples of tertiary prevention include rehabilitation counseling for a worker with an amputated limb, mobility training for a newly blinded person, vocational training for a mobility-impaired person who works at a job that requires a great deal of physical activity, and speech therapy for a stroke victim with speech loss. Also, tertiary prevention involves training disabled persons so that they may prevent additional complications and disabilities, such as the chronic sores and urinary infections often experienced by persons with spinal cord injuries.

The epidemiologic concepts of incidence and prevalence are helpful in understanding the problems of prevention. Incidence refers to predictability or the rate at which people without a disease or disability will develop it during a specified period of time (such as a month or a year). Prevalence measures the number of people in a population with the disease or disability at a given point in time. For example, the incidence of infants at high risk for mental retardation is 3% of live births during a one-year period (Meyen, 1982). For 1983, this meant that 111,000 infants were added to the existing population of retarded persons. The prevalence of mental retardation in the United States is estimated at 1% of the population

(Meyen, 1982). Therefore, with a 1983 population of 232 million, about 2.32 million individuals are expected to be retarded. These data are used by planners to delineate parameters of the national problem and to determine targets to attain during the implementation of a national plan to prevent physical disabilities and mental retardation.

III. PREVENTION PROGRAM COMPONENTS

This section reviews the major components of a comprehensive prevention program.

A. Programs to Maximize Health Care

The rapid increase in health care costs have forced national health planners to seek alternative health care strategies. Many planners have attempted to refine the present system of health care delivery, while others have urged an expanded two-pronged attack: (a) provide accessible, high quality health care services to all Americans who need them and (b) institute effective programs of prevention to reduce the incidence and prevalence of disability in the population. By applying prevention strategies in a coordinated, systematic and effective manner, cost containment of health care and maximization of the current health care system will be realized. Specifically, a national prevention plan should attend to the following factors:

1. Improved Prenatal Medical Care. Prenatal care should be improved for the following reasons:

    a. to reduce risk of premature births,

    b. to reduce risk of low birth weight babies,

    c. to reduce risk of embryonic and fetal damage and injury related to smoking, alcohol and drug use, accidents, improper diets and nutrition, and prenatal metabolic disorders,

    d. to improve care for minority women, and

    e. to reduce the number of pregnancies among teenagers (15-19 years of age).

2. Improved Immunization Programs for Children. The revolution in medical research has resulted in the control of infectious diseases. For

example, smallpox has been eradicated from the world and the application of knowledge of immunology has led to the virtual elimination of diphtheria, tetanus, poliomyelitis (polio), measles, and rubella in the United States. Though immunization rates are high in the U.S., polio and rubella still occur at different times and in different population groups. If the United States is to maintain its good record in control of contagious disease, immunization rates must be kept high.

3. Mass Screening and Early Identification Programs. The process of early identification and appropriate follow-up assessment and treatment is essential to a preventive strategy. Since its purpose is to select individuals in the early stages of a disease or disorder, this strategy is often technically referred to as Secondary Prevention.

Early and accurate identification of potentially handicapping conditions is one of the most important prevention strategies. Unfortunately, it is underused and underrated. Mass screening for a range of disorders should be instituted on a systematic and periodic basis. It should focus primarily on infants and young children and high risk populations of adolescents, young adults and adults. Follow-up diagnosis and treatment must be provided for persons identified by screening tests as having health problems. Also, it is recommended that registries of high risk individuals be established, especially for children at risk in the 0 to 5 year group. After high risk infants are screened at birth, they should be screened one to three times between birth and age 5, and once again upon entering school.

Examples of mass screening programs are (a) hearing and vision screening of children and adults, (b) cancer screening for selected high risk groups (such as annual screening for rectal and colon cancer for persons over 50), (c) hypertension screening of youth and adults, especially Blacks, and (d) diabetes screening for obese persons and those with a family history of the disease.

4. Improved Health Maintenance Programs. Health maintenance programs should be emphasized to help disabled persons prevent decubitus ulcers, urinary bladder infections and deterioration of mobility. Treatment for and training of the disabled person to prevent these complications will reduce impairments resulting from the disability and help restore function. Unfortunately, tertiary prevention services are neither well developed nor frequently applied. Tertiary prevention should be emphasized in any national program of disability prevention.

5. Improved Accessibility to Medical Care for All Persons. Although Medicaid was expected to improve accessibility to primary health care for low income individuals, it presently covers only about one third of all families living in poverty. A recent study indicates that 75% of the nation's low income population do not have access to medical care to the extent realized by the middle and upper income levels of the population (O'Connor, 1985, p. 32). This means that a large segment of the population does not receive the periodic screening and testing that is considered an important preventive strategy for the U.S. population. Inaccessibility to primary health care delays necessary treatment and training and results in advancing the progression of a disease, disorder or disability.

6. Improved Environmental Quality Control. There is tremendous public interest in conserving our natural and national resources and the quality of our environment. As a developed country, the U.S. has witnessed the accumulation of vast amounts of waste and unwanted waste products which

contaminate our air and water and may become detrimental to human health. Pollutants also limit desirable living space, interfere with sanitation and adversely affect the full enjoyment of the natural environment. Since these problems do not respect geographical or political subdivisions, States need Federal assistance to achieve and maintain a uniform program of environmental quality control. Past experience suggests that Federal Government standards have been tighter than those imposed by the States. There is a need, therefore, for continued Federal enforcement of current laws and for new and more effective measures to maintain a healthful environment.

In planning for the improvement and maintenance of environmental quality, the following priorities are recognized: (a) the protection of the community water supply for consumption, recreation, and other appropriate purposes; (b) the control of air pollution; (c) disposal of refuse and waste; (d) occupational health and safety; (e) the reduction of noise pollution; (f) food and milk control; (g) radiation protection; and (h) control of toxic substances in buildings (Kruse, 1976).

B. Programs to Maximize Educational Growth and Sound Psychological Development

Under this heading are prevention measures which assist the individual to realize educational potential and social and mental well-being.

Improved and expanded community-based early intervention programs are needed for high risk disabled infants, young children and their parents. The largest group of retarded persons (about 85%), mildly retarded individuals, appear to result from multiple causes that include biological and/or environmental factors (Birch & Gussow, 1970; Hurley, 1970). Much mild retardation is now believed to result from the deprived sociocultural environment often associated with poverty, inadequate stimulation or improper nutrition. In children at risk for retardation because of sociocultural factors, considerable evidence supports the significance of early intervention and environmental modification to eliminate or ameliorate retarded development (Herber, 1978; Skeels, 1965, 1966; Crissey, 1977; Stedman, 1982; Meyen, 1982). Prevention program efforts result in marked changes in subsequent intelligence, educational, vocational, and social achievements of the children.

The Expanded Early and Periodic Screening Diagnosis and Treatment (EPSDT) program has been described as the finest Federal prevention-oriented initiative (O'Connor, p. 32, 1985). As a component of Medicaid, EPSDT requires States to pay for and ensure delivery of a wide range of preventive health care services to Medicaid-eligible children under the age of 21. Services through this program include comprehensive periodic screening and health assessments, remedial treatment, and assistance with transportation and scheduling. Despite recognition that this program is very helpful and needed, the States report that their EPSDT participation rate ranges from 15 to 30%. States should be encouraged to raise their participation rates so that all at-risk children are served.

Improved community-based services are needed to provide (a) child abuse prevention, (b) mental health counseling, (c) drug and alcohol counseling, and (d) geriatric services. The should include preretirement counseling, leisure time planning, depression prevention and preparation of high risk groups for possibility of chronic illness (such as cancer and stroke).

C. Programs for Public Education and Awareness

This prevention strategy refers to educating the community about prevention. The objectives of public education are to develop a prevention-oriented population which (1) has broad knowledge about prevention strategies and (2) is strongly motivated to move from the state of knowledge to action, behaving in ways which lead to and maintain good health.

Information about prevention should be disseminated as widely as possible at the local, State and national levels. The use of mass media (television, radio and the press) will play an important role if the campaign is systematic and continuous, if the exposure of the information to the public is appealing and receives priority status (that is, prime time on radio and television and front page coverage in newspapers), and if key public figures are associated with the campaign (Marge, 1981). In addition, it has been found that face-to-face instructional programs enhance the ability of the mass media program to promote positive health behavior in the general population (Maccoby, 1980). Intensive face-to-face instructional programs for certain segments of the community reinforce the concepts communicated by the media campaign. For example, a public media anti-smoking campaign will have a decided impact on light smokers. But if the campaign were associated with a community-based instructional program (for example, through the Red Cross or the American Lung Association) to teach smokers to reduce or eliminate their habit, the prevention effort also will have a decided impact on moderate and heavy smokers. In a study by the Stanford University Heart Disease Prevention Program, the combination of face-to-face meetings and a media campaign resulted in changed lifestyles and health behavior in a substantial number of individuals who were surveyed by the study. About 50% of the smokers surveyed stopped smoking three years after the education program began (Maccoby, p. 208, 1980). Behaviors under the control of the individual could be influenced by the public education programs listed below.

1. Primary Disease Control Programs. Primary disease control programs inform and attempt to persuade the individual to make lifestyle changes, including eliminating smoking, restricting the use of alcohol, exercising strenuously three or more days per week, controlling weight (within recommended weight ranges) for height, build and sex, obtaining appropriate amounts of vitamins, minerals, and fiber, controlling stress, and having periodic examinations and tests.

2. Accident Prevention. Accident prevention requires the individual to follow safety precautions at home, at work, during leisure and recreational activities and during travel. Specifically, the precautions listed below should be emphasized.

(a) The use of auto child restraint seats and seat belts by occupants of autos.

(b) The use of helmets for motorcyclists and bicyclists.

(c) The observation of safety factors in the home to include fires, burns, poisonings, electrical shocks, drownings, and falls.

(d) The observation of pedestrian safety rules.

(e) The awareness of safety practices during recreation and sports activities: avoiding diving accidents, accidents during the use of trampolines and during the play of contact sports, especially football and soccer. Attention to performance standards of protective sports equipment and the need to improve the rules of play for contact sports to eliminate unnecessary exposure to risk of injury, are important. For example, "piling on" in football should be prohibited. It has been one of the main reasons for serious disabling injuries in a player whose body is crushed under the weight of five or more opponents.

(f) The application of occupational health and safety precautions following national and voluntary regulations to protect the worker from exposure to dangerous substances and work circumstances.

(g) The use of safety measures on playgrounds, especially for integrated play areas. For example, small smooth pea gravel or beach sand at least 10" thick should cover the entire region of the playground as a "cushion" against falls from heights of six feet or more.

3. Educational Programs in the Schools. Such programs should focus on health education and health promotion. Throughout the elementary and secondary school program, children should receive information and training in disease and injury prevention and health promotion (Marge, 1981). Curriculum units should include education for parenthood, preparation for the major transitions in life (adolescence, adulthood, older adulthood, leaving home, getting married, and death), and preparation for major life crises (death of a loved one, birth of a child, financial difficulties, loss of a job, sexual problems, and so on). To break the cycle of child abusive behaviors, the curriculum should stress appropriate child rearing practices and the prevention of child abuse. Such information should be introduced in a manner and sequence that is appropriate for the age and maturity of the student.

Christoplos and Valletutti view education as the "essential means of prevention" and call for a massive education program to teach individuals to behave in ways that minimize the likelihood of their becoming disabled (1979, p. 9).

IV. PROBLEMS

A. Need for Coordination of Prevention Efforts

Effective coordination of prevention efforts is needed among agencies at the Federal, State and local levels. With exceptions, prevention programs have been generally limited, redundant and unfocussed. As an example, the Surgeon General's effort to reduce smoking among Americans is countered by the large subsidies to the tobacco agricultural enterprise through the U.S. Department of Agriculture. In 1983, the Federal Government sustained $93 million in losses on loans to tobacco farmers and expects $450 million to $1 billion in further losses over the next three years (American Lung Association, 1985). In 1984, the tobacco industry spent an estimated $1.5 billion to promote smoking; the Federal budget for antismoking education is less than $10 million (Richmond, p. 3, 1985).

At the State level, efforts to reduce or eliminate teenage drinking and driving have been notably limited. Part of the problem rests with the aggressive sales pitch and advertising campaign of the alcoholic beverage industry. Despite State laws prohibiting drinking at 18 or 21, alcohol intake is still actively encouraged and readily available to teenagers.

At the local level, there is little coordination among local chapters of service organizations and agencies that fund efforts to reduce or eliminate smoking behavior. Local chapters of the American Cancer Society, the Red Cross, the American Lung Association and the American Medical Association all broadcast individual advertisements to discourage the public from smoking. Better coordinated and focussed efforts should result in a greater public knowledge and reduced smoking behavior.

Despite the laudable efforts of the Office of Disease Prevention and Health Promotion of the Department of Health and Human Services, the attainment of many objectives delineated in their National Plan (U.S. Department of Health and Human Services, 1980) has been delayed. Part of the problem is related to the fact that the Office of Disease Prevention and Health Promotion does not have a clear and direct mandate to effect coordination among Federal agencies and therefore must rely on goodwill and persuasion. More will be said about the role of the Office of Disease Prevention and Health Promotion later.

B. The Need for Personnel to Institute and Conduct Programs of Prevention

There is a growing interest in training health related professionals, educators and community-oriented workers in the area of prevention. There is a need for community leadership to plan and implement programs of disability prevention. Physicians, public health nurses, social workers, speechlanguage pathologists, audiologists, special educators, rehabilitation counselors, in the administrators health-related professions and public spirited citizens could provide such leadership after each has been trained in disease and injury prevention and health promotion. A new and emerging specialization is on the horizon--the community prevention specialist (Marge, 1984).

C. The Need for Legislation and Governmental Funding to Support Prevention Program Components

The Federal Government should play a role in encouraging States and local communities to institute comprehensive coordinated community-based programs which realize the highest usage of auto seat belts, child auto restraint seats, smoke detectors in the home, early identification and early intervention for high risk infants and young children, the promotion of good health practices and the use of safety precautions as described earlier.

With regard to community-based prevention programs, five primary constituencies need to be recognized: the public, the medical/professional health community, business and industry, government at all levels, and foundations and many private voluntary organizations (Rodale, p. 40, 1985).

D. The Need for Physical Fitness Programs to Accommodate Disabled Persons So That Further Deterioration Does Not Occur

Tertiary prevention attempts to restore as much effective functioning as possible and to prevent further complications. There is need for a more coordinated and concerted effort to educate and train disabled persons in disease and injury prevention and health promotion and to better monitor their health status as a form of early identification.

E. Economic Considerations

The implementation of a national prevention program will require additional Federal dollars. At a time when Federal budget planners are seeking ways to reduce spending on domestic programs, it appears fruitless to recommend expanded program budgets for disease and injury prevention and health promotion and new monies for coordinated States and community prevention programs. But the "penny wise and pound foolish" adage holds true in the area of prevention. For example, while adequate prenatal care can be provided for as little as $250 to $350 per patient, the cost of care for premature (and thus low birth weight) infants can be 100 times that amount (Petty, p. 37, 1985). Petty states, "Clearly, it is tragic and foolish for society to pay $20,000 to attempt to rescue a sick premature baby, and $1 million to care for a handicapped child, but refuse to pay $250 to prevent the conditions which led to those costs" (p. 37, 1985).

Another example of recommended budget and program expansion is the WIC program (Special Supplement Food Program for Women, Infants, and Children). This program was initiated in 1972 to provide nutritious foods, food education and referral to health care services to pregnant, post-partum and lactating women, and infants and children up to the age of 5, who are low income and at nutritional risk. Studies indicate that this program has reduced the incidence of low birth weight infants and infant mortality.

In addition to the need to expand programs and budgets to support broader access to good medical care, nutritional counseling and services and early identification and treatment, the Federal Government needs to provide leadership and modest support to encourage States and local communities to mount comprehensive and effective prevention programs.

V. LEGISLATIVE AND PROGRAM REVIEW

A number of Federal programs that contain program components related to prevention activities are described below.

A. Maternal and Child Health and Crippled Children's Services

Title V of the Social Security Act of 1935, as amended, authorizes grants-in-aid to the States, special project grants and research and training support to further the development and improvement of a national system of services to reduce infant mortality, enhance prenatal and post-partum care, and ameliorate the effects of handicapping conditions originating in childhood (U.S. Department of Education, 1980). In the area of primary prevention, this legislation supports prenatal care, nutrition programs, well-baby clinics (screening, early identification and intervention), disease and injury prevention, and immunization.

The legislation also supports public awareness programs and training programs for providers, and patients about good health practices. The Federal Fiscal Year, 1985 budget is $478 million.

B. The Education of the Handicapped Act

This Act is the chief source of Federal support for aid to State and local educational agencies for educational and special services to handicapped children. The major part of the legislation is "a State grant-in-aid program which requires participating States to furnish all handicapped children with a free, appropriate public education in the least restrictive environment" (U.S. Department of Education, 1980).

With regard to prevention, the legislative program focus is primarily on secondary and tertiary prevention. The program encourages States to mandate special services to at risk and handicapped children from birth to five years of age. At present, 42 States mandate services to some portion of this age group. Nineteen States mandate services to all three to five year olds requiring attention. A few States provide support services to infants and young children. In order to prevent disabilities in at risk children and to intervene with children at the first discernible sign of a developing disability, the legislative program should be expanded to accelerate State concern, and responsibility for children from birth to five years of age.

In Fiscal Year 1985, 4,341,399 handicapped children were served under this program with a Federal budget of $1.135 billion.

C. Community Mental Health Block Grants

This legislation has provisions which refer to each of the three stages of prevention. Support is available for Child and Adolescent Service System Programs, Community Support Programs and Prevention Programs administered by the National Institute of Mental Health.

D. Rehabilitation Act of 1973

This legislation authorizes over a billion dollars in Federal support for training and placing mentally and physically handicapped persons into remunerative employment (U.S. Department of Education, 1980). Under this Act, a wide variety of service, demonstration, training and research grant programs are established, including a major Federal-State grant-in-aid program. Programs focus on tertiary prevention, though some components may be interpreted as secondary prevention. In Fiscal Year 1985, the number of clients served is about 1 million at a budget of $1.1 billion.

E. National Institutes of Health (NIH)

Title IV of the Public Health Service Act authorizes a number of biomedical research activities which relate to the diagnosis, treatment, and prevention of various types of disabling conditions. All stages of prevention are considered by the NIH with the primary focus on medical approaches. For example, the Division of Prevention and Special Mental Health Programs of the National Institute of Mental Health (NIMH) supports intervention research aimed at the promotion and maintenance of mental health. Amongs its specific responsibilities, the NIMH is to design national goals and establish national priorities for the prevention of mental illness and the promotion of mental health.

F. Health Care Financing Administration

A major component of this program is the Early and Periodic Screening Diagnosis and Treatment (EPSDT) which was discussed at some length in a previous section.

G. Other Related Program Efforts in Prevention

Other prevention related legislation is administered by the Office of Human Development Services (HHS), Department of Agriculture, Consumer Product Safety Commission, Environmental Protection Agency, Department of Labor (Occupational Safety and Health Administration), Department of Transportation (National Highway Traffic Safety Administration), Department of Education and the Justice Department.

VI. GAPS IN LEGISLATION AND PROGRAMS

This section reviews current deficiencies in Federal efforts to plan and implement a national prevention program. In the Fall of 1980, the Department of Health and Human Services issued a report entitled, "Promoting Health--Preventing Disease, Objectives for the Nation" (U.S. Department of Health and Human Services, 1980). The report delineates in considerable detail specific objectives and strategies for the nation to be attained by 1990. The objectives and strategies resulted from an intensive and complex process of deliberation by the Office of Disease Prevention and Health Promotion with all Federal agencies that administer prevention programs. Unfortunately, the National Plan has been implemented with only limited success. The primary reason is that the Office of Disease Prevention and Health Promotion and the Department of Health and Human Service did not have a clear and decisive mandate to effect the National Plan. Attempts by the Office of Disease Prevention and Health Promotion to meet objectives according to a timetable were based on persuasion and good will.

There is an immediate need for an organized and focussed Congressional and Administration effort to successfully coordinate existing Federal prevention program activities for the attainment of the Objectives for the Nation. Although the Objectives were written for implementation by the target date of 1990, because of the delay experienced by the Department of Health and Human Service, it is recommended that the Objectives be reviewed again with a new target date of the Year 2000.

The Objectives for the Nation are summarized as follows with some suggestions about immediate needs to be addressed.

A. Pregnancy and Infant Health

The Maternal and Child Health block grants have undergone funding cuts of 25-30%; the Women, Infants and Children (WIC) program serves only one-third of the eligible group and faces Federal budget cuts which will eliminate one million from the program. This objective focuses on low income women who do not have access to adequate health care during the time of pregnancy and for their infants and young children.

B. Immunization

Recent efforts by State and local educational agencies to require all school children to be immunized has been one of the most effective means for improving immunization levels. Though most school-age children are immunized, many preschool children are not. Also, high risk populations should be receiving annual immunizations against certain disabling diseases such as influenza and pneumococcal pneumonia. Federal efforts should be directed to 100% immunization of all preschool and school-age children and individuals who are considered at high risk (such as the debilitated child or an elderly person who is in need of protection against a dangerous strain of influenza).

C. Toxic Agent Control

Toxic agents include natural and synthetic chemicals, dusts (such as asbestos), minerals, certain materials and radiation which produce acute or chronic illness. Exposure to these agents may result in systemic poisoning, teratogenic abnormalities and growth impairments, cancer, neurologic disorders, behavioral abnormalities, immunologic damage, and chronic degenerative diseases involving the major organs of the body. Legislative and regulatory measures which relate to this area of concern include the Clean Air Act, Clean Water Act and the Safe Drinking Water Act; Resource Conservation and Recovery Act; Toxic Substances Control Act; Federal Hazardous Substances Act, Consumer Product Safety Act; Federal Environmental Pesticide Control Act; the Food, Drug, and Cosmetic Act; Hazardous Substances Transportation Act; Atomic Energy Act; National Environmental Protection Act; Occupational Safety and Health Act; Federal Insecticide, Fungicide and Rodenticide Act; and Radiation and Safety Act. There is need for effective coordination of these legislative programs through a mechanism such as an Interagency Regulatory Liaison Group. Also, there is a need to coordinate public information about problems and developments related to toxic agents and to alert American citizens about current and potential hazards and how they may protect themselves.

D. Occupational Safety and Health

Worksite conditions may expose employees to health risks such as chemicals, asbestos, coal dust, heavy metals, cotton fiber, ionizing radiation, physical hazards, excessive noise and stress. These factors could result in disabilities related to cancers, lung disease, heart disease, birth defects, sensory defects, injuries and psychological problems. It is necessary to protect the worker by educating him or her about potential hazards, by instituting strict regulatory efforts to promote safety and health (using both governmental and voluntary regulations) and by continuing an active program of research on these problems. The Occupational Safety and Health Administration and the Mine Safety and Health

Administration are responsible for establishing and enforcing standards to protect the worker, but the enabling legislation administered by these agencies hold employers responsible for creating a safe and healthy work environment. Despite the attempts to regulate the work environment, the Federal Government--business and industry partnership needs to be improved. For example, the National Safety Council reports that in 1983, 1.9 million workers experienced injuries. Of this number, 70,000 were permanently impaired (National Safety Council, p. 26, 1984). During the past decade, an estimated 750,000 workers were permanently injured. This area of prevention can greatly reduce the incidence of adult disabling conditions.

E. Accidents and Injury Prevention

In 1981, an estimated 59 million people incurred nonoccupational injuries. Of this number, 27 million occurred in and around the home. The lost productivity cost the nation an estimated $55 billion. The major causes of accidents are associated with accidents involving motor vehicles, falls, drownings, burns, poisoning and gunshot wounds. Federal efforts in this area of disability prevention have been piecemeal. There is a great need for public information and education, legislative, regulatory and economic measures to reduce or eliminate the risk of injury resulting from accidents.

F. Smoking and Health

The Public Health Service has identified smoking as the single most important preventable cause of death and disease. In addition to damaging the health of heart and lungs, smoking is a major contributor to death and injury from fires, burns and other accidents. Twenty-nine percent of fatal house fires and a substantial number of burn injuries are smoking-related. Of particular concern is the inconsistency in Federal program goals for this major national health hazard. The Department of Health and Human Services urges Americans to refrain from smoking but the Department of Agriculture supports tobacco production.

G. Misuse of Alcohol and Drugs

The major purpose of this significant area of prevention is to reduce the adverse effects of alcohol and dangerous substances on adolescents, young adults, pregnant women, and the elderly. An estimated 10% of the adult population 18 years and over are frequent heavy drinkers. Approximately 2.5 million persons have serious drug problems. The public and private sectors have had a limited impact on these problems through efforts for public education and alcohol beverage and drug regulation. There is a great need for community-based efforts to reduce the consumption of alcohol and drugs.

H. Nutrition

This prevention issue relates to the excessive or inappropriate consumption of nutrients. Inadequate nutrition is associated with pregnancies which produce low birth weight infants with retarded mental and physical development. Public education, nutrition training and counseling, and accessibility to adequate health care, especially by persons with low incomes, are necessary if this problem area is to improve. The Federal Government must increase its efforts to eliminate the problems created by nutritional inadequacies.

I. Physical Fitness and Exercise

As a primary prevention measure, regular and reasonable exercise reduces the risk of cardiovascular disease, obesity, diabetes, musculoskeletal problems, respiratory diseases, stress and depression. Certain groups are reported to have lower rates of participation in appropriate physical activities. These include girls and women, older people, physically and mentally handicapped people of all ages, inner city and rural residents, people of low socioeconomic status and residents of institutions. Governments at all levels should encourage physical fitness and exercise through a coordinated program of public information and education. Fitness-related activities should be allowed under federally funded programs.

J. Control of Stress and Violent Behavior

Stress management programs are of high priority because the socioeconomic impact of contemporary psychosocial stress and its biologic devastation is considered to be potentially enormous. It can lead to such phenomena as fatigue, headache, obesity, absenteeism, coronary disease, suicide, accident-proneness and violence. Research has demonstrated various associations between stress and health and disease. It appears that teenagers, the elderly and persons with low incomes are especially vulnerable to stress. The general public has limited information about what can be done to reduce stress. There is need to step up research on stress and its control and to inform and educate the public about current knowledge of stress management.

Suicide and homocide are associated with stress. Federal programs can play a significant role in reducing the incidence of these two behaviors by assisting programs which teach individuals to cope and manage stress, by supporting programs for alcohol and drug misuse, by providing leadership in national gun control legislation (especially handguns), by publicizing the early signs of potential suicide and steps to take to prevent a person's suicide, and by supporting further research in stress and violent behavior control.

VII. OTHER CONSIDERATIONS

As was stated earlier, there is a need for systematic, standardized and community-based programs to screen infants and young children and other selected age groups of the population to determine if health problems may develop or have developed. If problems are found, the appropriate intervention program should be applied immediately to reduce the probability that a chronic disability will develop. This is especially important for infants and children who are at risk for physical and mental disabilities. Such interventions are cost effective when infant and child behaviors indicate early signs of disability. Federal programs have supported early identification and intervention (Secondary Prevention) for high risk infants and children. Program support should be expanded until all children can benefit from such program efforts. There is a need for leadership at the Federal level to encourage State and local governments to mandate such services to potentially handicapped children from birth to five years of age.

Another area of concern is support for mental health programs. Reduced Federal spending has resulted in reductions in necessary services for children and adults with mental disabilities. For example, there is a shortage of trained mental health personnel to provide services for children.

Another area of concern relates to individuals who are already disabled. It is often assumed that once a program of therapy and special services is administered to a disabled person, the process of intervention is terminated. This static perception of health care for disabled persons ignores the fact that disabilities may become worse or the individual may develop other physical and mental problems which further complicate efforts at rehabilitation. There is a need to monitor and follow-up on all cases of disability and to intervene as necessary to prevent further deterioration. Federal programs related to disabled children and adults should include provisions for follow-up and monitoring.

VIII. RECOMMENDATIONS

The recommendations which follow are predicted on a number of assumptions related to prevention programs. First, it is assumed that the National Council on the Handicapped should play an important role in the development of a National Plan for the Prevention of Disabilities. Second, although the national plan of the Department of Health and Human Services, "Objectives for the Nation," focuses on fatality rather than disability, the plan does provide a good foundation for the development of the National Plan for the Prevention of Disabilities. Third, the Office of Disease Prevention and Health Promotion, Department of Health and Human Services, which coordinated the development of the 1990 Objectives for the Nation, possesses the expertise, resources and experience needed to assist the National Council in the development of a National Plan for the Prevention of Disabilities and to assume the major responsibility for implementing the Plan. Fourth, the major emphasis of the Prevention of Disabilities Plan will be the coordination of Federal prevention-related programs and activities. Governments and organizations at the State and local levels will be encouraged to establish coordinated, comprehensive programs for the prevention of disability. Fifth, the "partnership" between the National Council on the Handicapped and the Office of Disease Prevention and Health Promotion will work only if the partnership is given a clear mandate by the Congress. The mandate should be to develop and implement a national plan. If these responsibilities are not mandated by Congress, "turfism" and historical barriers will continue to prevent effective cooperation. The Federal plan should stress coordination of existing resources and programs, public education and persuasion, the expansion of some Federal programs, the addition of several new Federal programs related to prevention, and disability prevention research. Sixth, it is assumed that most of the necessary resources are already available at the Federal, State and local levels. Seventh, Americans must personally accept more responsibility for disability prevention than they have in the past by making lifestyle changes and applying safeguards against disease and injury. And eighth, it is assumed that a community-based model of prevention (or a grass roots approach) is more effective than a centralized governmental model based on governmental control. Therefore, the Federal Government should provide leadership in disability prevention by coordinating its own programs and consolidating its resources, by encouraging States and local communities to plan and implement prevention programs at their levels, and by monitoring the regulations and program efforts related to prevention.

1. Congress should enact a law related to prevention entitled "The Prevention of Disabilities Act."

The Act should have three chief provisions: a) authorize the National Council on the Handicapped to establish policy and goals for a National Plan on the Prevention of Disabilities, and to review and make recommendations regarding implementation of the Plan; b) require the Office of Disease Prevention and Health Promotion (Department of Health and Human Services), working with the National Council on the Handicapped and other appropriate Federal agencies, to oversee the development and implementation of the National Plan; and c) authorize a small grant program to support the development of coordinated, comprehensive, and effective prevention programs by States and local communities. The grant program should be administered by the Assistant Secretary of Health. Implementation of this recommendation should require only a small number of additional staff and some operational funding to support the implementation of Parts a and b above. In addition, the small grant program (Part c) would require only minimal funding support over a five year period.

2. Congress should provide appropriate levels of funding for special program priorities related to disability prevention.

The appropriation of funds for specific program priorities should include: a) prenatal care through the Maternal and Child Health Care program, Medicaid, and the Women, Infants, and Children (WIC) program (at no less than Fiscal Year 84 levels); b) preschool educational services through block grants to State educational agencies; c) educational programs for professional personnel, parents and children in disability prevention; d) dissemination of information about disability prevention to minority groups, chidren and adolescents through public education programs and curriculum units about prevention in elementary and secondary schools; and e) development of methods for preventing secondary disability among those already disabled.

3. Congress should direct its Office of Technology Assessment to conduct a study of the status of primary and secondary prevention of disability in the United States, and to submit a report of its findings two years after the issuance of the National Plan on the Prevention of Disabilities.

The authorization would provide for an objective, independent assessment through the Office of Technology Assessment of the status of primary and secondary prevention efforts in the United States, and of compliance with the National Plan.

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TOPIC PAPER E:

TRANSPORTATION

National Council on the Handicapped

February, 1986

ACKNOWLEDGMENT

This is one of a series of ten topic papers developed by the National Council on the Handicapped as part of its Special Report to the President and Congress: TOWARD INDEPENDENCE: An Assessment of Federal Laws and Programs Affecting Persons with Disabilities--With Legislative Recommendations. The members of the National Council on the Handicapped wish to expressly acknowledge with appreciation the special contribution made to this paper by Laura Rauscher.

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I. INTRODUCTION

The Urban Mass Transit Act, as amended in 1970, established transportation service for disabled people as a basic element of Federal transportation policy. The Act states that disabled people have the same right to use public transportation as nondisabled persons. Specific language that promotes the same principle is included in the Federal-Aid Highway Act of 1973. Since 1970, the nation has begun implementing accessible transportation systems in compliance with this policy. This paper assesses progress to date and recommends approaches to transportation accessibility which build on past experience.

Approximately 7.4 million persons are transportation-handicapped, according to Department of Transportation estimates. Transportation handicaps vary, ranging from individuals who have difficulty climbing stairs, reading signs, hearing announcements and understanding transit information to wheelchair users. In general, persons with transportation handicaps have lower incomes than other Americans, and are more dependent on public transportation to conduct the business of their daily lives. In fact, a major impediment to employment among people with disabilities is their inability to reach the job site due to the lack of available accessible transportation.

Regulations designed to implement legislative requirements for accessible urban transportation systems have changed several times during the past 15 years. They have ranged from minimal "special efforts" and "local options" to requirements for almost immediate full accessibility. Current regulatory efforts concentrate on setting performance criteria for services which can be designed in response to local conditions. These regulations are not yet final, two years after they were due. However, a recent case in Federal court in Maine has resulted in a court order requiring Secretary Dole of the Department of Transportation to issue those regulations by December 13, 1985. The Council believes that persons with disabilities should have the same access to transportation and equivalent service levels as that available to the rest of the service population.

The Council has reviewed the implementation of the transportation policy of this nation. We find that in most parts of the country we are far short of achieving accessible, usable transit systems. A 1982 survey conducted by the General Accounting Office indicated that nearly three-fourths of the urban rail stations surveyed were almost totally inaccessible to wheel chair users. The same study determined that one-third of the transit systems offering fixed-route bus service did not have a single bus with a lift. A recent American Public Transit Association (APTA) fact sheet reported that 76% of the 49,000 buses in use in this country are not accessible. Air travelers who use wheel chairs face a multitude of problems, ranging from uncomfortable, dangerous, and dehumanizing boarding procedures to inaccessible restrooms and boarding areas. Intercity/interstate bus service, the primary mode of public transportation for many people in rural areas, is almost totally inaccessible to transportation-handicapped persons. Modified vehicles, the only reliable transportation available to many persons with disabilities, particularly in rural areas, are often prohibitively expensive for individuals and families with limited incomes.

Although the general picture currently appears bleak, the Council has identified cost-effective, working models of usable, accessible transportation systems. Seattle, Washington; Champaign-Urbana, Illinois; Dayton, Ohio; Johnstown, Pennsylvania; and Palm Beach, Florida have successful, accessible public transit systems in place that meet the transportation needs of most of their citizens in a cost-effective manner. In addition, some interstate bus systems have attempted to develop accessible bus service, and some airlines, most notably, United Airlines, provide effective, courteous service for persons with travel disabilities. Amtrak has developed a model transition plan for accessibility that looks very promising.

The Council has concluded that accessible transportation is a critical component of a national policy that promotes the self-reliance and self-sufficiency of people with disabilities. People who cannot get to work or to the voting place cannot exercise their rights and obligations as citizens. Accessible transportation will become increasingly important in coming decades as our population grows older and experiences the increased transportation handicaps associated with an aging population. Providing only "special" van service and modified private vehicles is too expensive an option to meet the needs of this growing population, as is retrofitting tomorrow the mass transit systems being built or renovated today. The nation's experience with accessible transportation over the last 15 years suggests that cost-effective alternatives are available. The time has come to make our nation's policy of accessible transportation a reality in our communities.

II. URBAN MASS TRANSIT

In today's highly mobile society, transportation barriers continue to exclude many disabled persons from using most forms of public transportation. Such discrimination prevents many persons from realizing their full potential for independence and productivity. A National survey conducted by the Department of Transportation in 1978 estimated that there were "7.4 million transportation-handicapped persons in the urban United States, which represents 5% of the urban population" (DOT/UMTA, 1978, pg. 12). Section 16(c) of the Urban Mass Transportation Act of 1964, as amended, defines a person with a transportation handicap as:

> any individual who by reason of illness, injury, age, congenital malfunction, or other permanent or temporary incapacity or disability, is unable without special facilities or special planning or design to utilize mass transportation facilities as effectively as persons who are not so affected.

In this DOT/UMTA national survey, the urban transportation-handicapped population was separated into five categories:

1. Persons who use wheelchairs
2. Persons who use one or more mechanical aids such as braces, crutches, walkers, canes, or artificial limbs
3. Persons who have trouble seeing
4. Persons who have trouble hearing
5. Persons who have other problems such as difficulty in going up or down steps, stooping, kneeling, or traveling more than one block.

The survey estimated the following numbers of people in each group:

- o 409,200 people, or 5.5% of the transportation-handicapped population, use wheelchairs.
- o 1,938,600 people, or 26.1% of the transportation-handicapped population, use one or more mechanical aids or prosthetic devices.

- 1,566,000 people, or 21.0% of the transportation-handicapped population, are visually impaired. This population includes 259,100 people (3.5%) who are blind.
- 1,572,800 people (21.2%) are hearing impaired, including 371,700 who are deaf (5.0% of the transportation-handicapped population).
- 3,502,300 people, or 47.1% of the tranportation-handicapped population experience other problems.

Of the 7.4 million persons who were identified as transportation-handicapped, only 1.1 million, or 15%, were employed at the time of the DOT survey. Of working age, transportation-disabled persons, just 23% were employed, as compared to 64% of the total working age population.

Employment opportunities can, however, be expanded through the increased availability of accessible public transportation. According to the Department of Transportation:

> ...the opportunity to get a job is a potential benefit of accessible transportation for a substantial number of handicapped people (DOT/UMTA, 1978, pg. 45).

The Governor's Transportation Task Force for Individuals with Disabilities in the State of Illinois recently conducted a study of the transportation needs of disabled and elderly persons in their State. The study shows that accessible transportation is essential for reaching education and employment goals:

> Almost 41% of the persons served by vocational rehabilitation agencies felt they needed transportation to and from work, and 22.3% indicated they would need transportation to attend the training and educational programs they needed to prepare themselves for work. In a survey of vocational rehabilitation service providers, 87% felt that the lack of affordable transportation was a major impediment to serving persons with severe disabilities and locating job placements for them. By the same token, transportation problems were the second-leading cause identified in a survey of severely disabled vocational rehabilitation clients who had not successfully completed their service plans (GTF Illinois, June 1985).

Investments in education and vocational rehabilitation offer a hollow promise if the end goals of independence and employment remain out of reach due to limited access to transportation.

A. Legislation

Since 1964, four major pieces of legislation have affected urban mass transportation for disabled people. They are:

1. Architectural Barriers Act of 1968
2. Federal-Aid Highway Act of 1973
3. Rehabilitation Act of 1973
4. Urban Mass Transit Act of 1964, as amended in 1970 by the Urban Mass Transit Assistance Act, and in 1984 by the Surface Transportation Assistance Act.

A brief synopsis of the provisions of these laws follows.

1. Architectural Barriers Act of 1968. The Architectural Barriers Act defines certain buildings, subject to the provisions of the law, which must be made accessible. It requires four Federal agencies, the General Services Administration, Housing and Urban Development, the Department of Defense, and the United States Postal Service to set standards to ensure that whenever possible physically handicapped people have ready access to and use of buildings which are designed, constructed or altered with certain Federal funds. The handicapped-access standards established by these four agencies are enforced by the Architectural and Transportation Barriers Compliance Board (ATBCB), which sets minimum guidelines and requirements or the parameters for the standards.

Since the Department of Transportation (DOT) is not a standard setting authority under this Act, the ATBCB has no authority to set minimum guidelines and requirements or to enforce transportation access standards that DOT may develop. Some facilities, such as certain bus terminals and train stations, are covered by the Architectural Barriers Act. The Act does not, however, cover the accessibility of vehicles, buses and trains associated with those transportation facilities.

2. Federal-Aid Highway Act of 1973. In 1973 the Federal-Aid Highway Act, Section 165(b), as amended by the Federal-Aid Highway Amendments of 1974, provided further clarification of what was required and implies a much stronger intent to have services accessible as part of all operations:

> The Secretary of Transportation shall require that projects receiving Federal financial assistance under (1) subsection (a) or (c) of section 142 of title 23, United States Code, (2) paragraph (4) of subsection (e) of section 103, title 23, United States Code, or (3) section 147 of the Federal-Aid Highway Act of 1973 shall be planned, designed, constructed, and operated to allow effective utilization by elderly or handicapped persons who, by reason of illness, age, congenital malfunction, or other permanent or temporary incapacity or disability, including those who are nonambulatory wheelchair-bound and those with semi-ambulatory capabilities, are unable without special facilities or special planning or design to utilize such facilities and services effectively. The Secretary shall not approve any program or project to which this section applies which does not comply with the provisions of this subsection requiring access to public mass transportation facilities, equipment, and services for elderly or handicapped persons. (Emphasis added.)

In addition to a declaration of national policy, the strong language underlined above was added by the 1974 amendment. As with the Urban Mass Transportation Act, judicial interpretation has found that the Federal-Aid Highway Act "does not require every standard size transit bus to be totally accessible to mobility handicapped persons" (U.H.F. v. Andre, 1976).

3. Section 504 of the Rehabilitation Act of 1973. Section 504 prohibits discrimination against a person on the basis of handicap. It says:

> "No otherwise qualified handicapped individual in the United States...shall, solely by reason of his handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance or under any program or activity conducted by any Executive Agency or by the United States Postal Service..." (Section 504, Rehabilitation Act, 1973).

The language of Section 504, though it covers the provision of federally-assisted transportation, provides little guidance about what must actually be done. The language closely parallels civil rights legislation; in fact, it was originally introduced as legislation to include handicapped persons within the list of groups protected under Title VI of the Civil Rights Act. It has been interpreted by the courts as not only expressing substantive rights of disabled people, but also as conferring a private right of action to enforce the statute. Although like other Civil Rights legislation this law clearly prohibits discrimination, it has not been interpreted by the courts as providing a strong statutory basis for full accessibility in transportation.

Little congressional debate took place prior to the passage of Section 504. As a result, there is little legislative history to help us understand congressional intent with respect to Section 504's effect on transportation. Even so, its general prohibition against discrimination is important and far-reaching.

It has been suggested by several transportation experts that little discussion took place about transportation issues in Section 504 because Congress believed they had been explicit enough in the Federal Highway Act of 1973 about their intent to provide equal transportation services for disabled persons. The ongoing regulatory change and court decisions since that time challenge that assumption intent.

4. Urban Mass Transit Act. The Urban Mass Transit Act of 1964, as amended by the Urban Mass Transit Assistance Act of 1970 and the Surface Transportation Assistance Act of 1982 (Section 16) states the following:

> "It is hereby declared to be the national policy that elderly and handicapped persons have the same right as other persons to utilize mass transportation facilities and services; that special efforts shall be made in the planning and design of mass transportation facilities and services so that the availability to elderly and handicapped persons of mass transportation which they can effectively utilize will be assured; and that all Federal programs offering assistance in the field of mass transportation (including the programs under this chapter) should contain provisions implementing this policy" (UMTA, 1970).

The powerful language in this Act declares a right to equal use of public transportation for disabled and elderly persons. It expresses congressional intent to assure that disabled people must be provided equal access to public mass transit. However, the statement of rights for disabled people in the Urban Mass Transportation Act is too ambiguous. In this statement of "national policy," a right is declared, but it lacks the underlying foundation necessary to render it enforceable. It contains no clear mandate.

Another part of this statutory section contains the most controversial term in the accessibility issue: "special efforts." The Act requires that "special efforts shall be made in the planning and design of mass transportation facilities and services so that the availability to elderly and handicapped persons of mass transportation which they can effectively utilize will be assured..."

This part of the Act weakens the statement of rights of handicapped and elderly persons because the only aspect of implementation which requires special efforts is in planning and design. It does not set a physical standard for compliance; it does not clarify whether the right conferred is actually exercisable. Judicial interpretations have found that this section creates no requirement for a fully accessible system.

The legislative history of the Act, on the other hand, tends to support the idea that the intent of Section 16 is to create full accessibility. The chief supporter of the amendment creating the present Section 16, Mario Biaggi, stated:

> "Heretofore handicapped Americans were relegated to separate and unequal transit systems--systems that were very costly not only to the Government, but also to the individual user. My 1970 amendment sought to require that design and construction of all new mass transit systems, equipment, and facilities be totally accessible to the elderly and handicapped" (Biaggi, 1974).

On January 6, 1983, President Reagan signed into law the Surface Transportation Assistance Act, which amends the Urban Mass Transit Act of 1964. Section 317 states:

> (c) Section 16 of the Urban Mass Transportation Act of 1964 is amended by adding at the end thereof the following:
>
> "(c) In carrying out subsection (a) of this section, section 165(b) of the Federal-Aid Highway Act of 1973 (consistent with any applicable Government-wide standards for the implementation of such section 504), the Secretary shall, not later than 90 days after the date of the enactment of this subsection, publish in the Federal Register for public comment, proposed regulations and, not later than 180 days after the date of such enactment, promulgate final regulations, establishing (1) minimum criteria for the provision of transportation services to handicapped and elderly individuals by recipients of Federal financial assistance under this Act or under any provision of law referred to in section 165(b) of the Federal-Aid Highway Act of 1973, and (2) procedures for the Secretary to monitor recipients' compliance

> with such criteria. Such regulations shall include provisions for ensuring that organizations and groups representing such individuals are given adequate notice of and opportunity to comment on the proposed activities of recipients for the purpose of achieving compliance with such regulations" (Congressional Record, 12/21/82).

This legislation required notice of proposed rule making by April 6, 1983. Proposed rules were finally issued in October of 1983. Final rules were due July 6, 1983. To date they have not been issued.

The next section explains in more detail the changing regulatory phases and indicates the need for strong legislative action that will explicitly clarify congressional intent to provide equal access and comparable service levels to people with disabilities.

B. Public Transportation Accessibility Regulations

Transportation services for disabled persons have been identified as a national goal since 1970 when the Urban Mass Transit Act of 1964 was amended to declare it to be national policy that disabled people have the same right to use public mass transportation as nondisabled persons. This Act began a period of uncertain and changeable regulatory policy in the area of transportation. Today, in 1986, some 16 years since its passage, transportation regulations are still not final.

Since 1970, there have been four phases of regulatory policy. They have been described in a recent study conducted by the Urban Institute as "Special Efforts," "Full Accessibility," "Local Option," and "Comparability" (Urban Institute, 1985, I-12, 13). A brief explanation of each of these phases follows.

"Special Efforts" began in 1968 with the enactment by Congress of the Architectural Barriers Act which set specific standards for making buildings financed with Federal funds accessible to disabled people. In 1970, the Urban Mass Transportation Act was amended, adding Section 16 to give disabled persons the same right as others to use public mass transportation. It also required transit authorities to make "special efforts" to provide effective service to disabled persons. Regulations clarifying the meaning of "special efforts" were not issued until six years later, on April 30, 1976. Special efforts were "clarified" at that time to mean "genuine, good faith progress" in the development of service for handicapped persons "that is reasonable by comparison with the service provided to the general public and that meets a significant fraction of the needs of these persons within a reasonable time period" (DOT, 1976).

It is generally accepted that these regulations were intended to be a first effort. Because few systems were doing anything, there was little on which to base conclusions. The perhaps well-intentioned concept of special efforts became both problematic and controversial. Regardless of what was intended, "special efforts" was translated around the country as doing little or nothing. Transit authorities were often unclear as to what constituted enough effort. Many transit authorities did nothing at all or made token efforts which did not adequately meet the needs of the disabled people in their communities. Because of their "special" status, these programs were often the first to be eliminated when cutbacks became necessary. "Special" meant "extra" and was therefore expendable. Cutbacks in services which were often inadequate to begin with left disabled citizens in some areas with little or no services.

The "Full Accessibility" phase begins with the promulgation of regulations implementing the Rehabilitation Act of 1973 by the Department of Health Education and Welfare (HEW). HEW was directed to coordinate the writing of similar regulations by all Federal agencies. In 1980, the Department of Justice (DOJ) assumed responsibility for this coordination.

In 1979, the Department of Transportation (DOT) issued its "full accessibility" regulations implementing the nondiscrimination provisions of Section 504 of the Rehabilitation Act for public transportation systems receiving Federal financial assistance. Due to varying cost projections (some very high) of achieving "full accessibility," the American Public Transit Association (APTA) mounted a legal challenge to the 504 regulations. This led to a finding in 1981 by the U.S. Court of Appeals for the Washington, D.C. Circuit Court that Section 504 did not provide an adequate basis for these regulations and remanded them back to the Secretary of Transportation to determine if other laws applied. DOT, however, rescinded and rewrote the regulations.

Full accessibility is the goal we all hope to achieve. However, the regulations developed to implement this concept prescribed design criteria and were perceived by transit authorities as too restrictive to allow local variations. However, it should be recognized that it was during this phase of regulations that most of the current advances in accessible transportation were made. Since these regulations were rescinded, much deterioration and little progress has taken place.

The "Local Option" phase started with the recision in July, 1981, of the full accessibility regulations. Interim "local option" regulations were introduced outlining vague requirements that transit authorities make "special efforts" similar to those introduced in 1976. These regulations contained no mandate for accessible service to disabled persons.

"Local Option" is ineffective for many of the same reasons as "special efforts." Local option gave transit authorities the option to once again do nothing or nothing meaningful (Cannon & Rainbow, 1980b). With vague definitions of special efforts and no mandated levels of service provision, little has been accomplished.

In 1983, DOT issued new proposed final regulations which defined how services to disabled people should be "compared" with services provided to nondisabled persons. These regulations were intended to replace the local option interim rule and responded to a congressional requirement to establish minimum criteria for the provision of public transportation to disabled people.

According to the Urban Institute and other transportation experts, the burden of compliance with the regulations would be constrained by one of two proposed limits on the amount of money transit authorities are required to expend in meeting the minimum service requirements. One option would limit a transit authority's obligation in a given fiscal year to 7.1% of the annual average amount of the Federal financial assistance received for mass transportation purposes over the most recent three years. Another option would limit required expenditures to 3.0% of the average operating budget for the three proceding years. To determine whether they have reached the cost limit, transit authorities would include only the incremental costs of acquiring and operating accessible rolling stock and the costs of providing special services.

Such cost limits do not place a ceiling on the amount a transit authority may spend on services for disabled and elderly persons; the recipient can always choose to spend more. Nor do they constitute a minimum spending requirement. The cost limits place a constraint on the maximum obligation of a transit recipient in complying with the service requirements.

The proposed cost limits probably constitute the most controversial portion of the 1983 regulations. While the cost limits do not impose a mandatory ceiling on spending, local transit authorities cannot be compelled to spend additional funds once the limit is reached. Consequently, such cost limits could become ceilings on public transportation expenditures for disabled people. This would effectively undermine progress toward meeting established minimum service criteria. If minimum service criteria can be ignored for cost considerations, there is no way to guarantee a minimum level of service and the established service criteria may become insignificant.

The 1983 regulations set out a simple "self-certification" approach that depends solely upon self-reporting by local public transit agencies rather than affirmative monitoring by UMTA. From a legal perspective, self-certification does not seem to fully meet the requirements set forth by Section 317(c) of the Surface Transportation Act. It requires DOT to affirmatively monitor compliance of transit agencies with regulations prohibiting discrimination against disabled people. The General Accounting Office has found that in the past DOT's monitoring and enforcement activity has been extremely limited. According to the Urban Institute, some eleven years after the enactment of Section 504, the Federal Government has yet to initiate a single enforcement action for discrimination against disabled people in the provision of public transportation. Thus the need for stronger monitoring and enforcement procedures is evident.

An issue parallel to the issue of monitoring and enforcement is the need for planning and evaluation. Establishing workable transition plans that outline specific access goals and timelines makes monitoring, evaluation and enforcement more feasible.

The planning implementation, and evaluation process must involve disabled and elderly consumers in substantive and meaningful ways. The National Council on the Handicapped has taken a strong position with regard to consumer involvement. Its national policy states that...."Disabled people should play leading roles in creating, making policy for, administering and directing public and private disability-related programs at the international, national, state, and local levels" (NCH, 1984). It must be established in legislation that consumers have a right to play leading roles in the development of transportation policy and programs in a significant and meaningful way that extends far beyond final commentary. The process should also include agencies involved in or affected by transportation services for disabled and elderly persons, such as the Architectural Transportation Barriers Compliance Board (ATBCB), the National Council on the Handicapped (NCH), and other advocacy organizations.

The concept of equivalent service is important because access without quality means little. Dennis Cannon has outlined and defined those areas which must be considered when determining whether services are comparable or equivalent. They are:

1) Equivalent Service Range. Contrary to many assumptions, disabled people are dispersed throughout the general population and their travel needs are not significantly different from those of the general population (3,6). Thus, service for disabled persons should extend throughout the general service area and operate during the same hours as the system used by the general public.

2) Equivalent Transfer Frequency. For trips of comparable length, handicapped passengers should not be required to transfer any more often than able-bodied passengers.

3) Equivalent Fare. Disabled passengers should be charged a fare no higher than that of the general public for trips of comparable length.

4) Equivalent Travel Purpose. Like able-bodied people, people with disabilities should not be restricted by trip purpose.

5) Equivalent Trip Decision/Travel Time.

   a) Trip Decision Time: Like the able-bodied users, the disabled user of public transit should need to decide to travel no longer in advance than the average headway (time between vehicles) plus travel time to the stop.

   b) Travel Time: Travel time varies according to the type of service (i.e., local or express).

   These two parameters are grouped since they balance each other. For example, an able-bodied user of transit may have access to a bus line with twenty minute headway and one hour (local travel) time. An alternative service for disabled people may require one hour advance notification and "express" travel to complete the trip in twenty minutes. Taken together, average trip decision time and travel time for a handicapped passenger should be equivalent, on the average, to that of the able-bodied passenger.

6) Equivalent Capacity. Able-bodied users of public transit may occasionally be confronted with a full vehicle but never a closed transit system. Many objections have been raised in the transit industry about accessible line-haul bus service with the question "What good is an accessible bus if the handicapped person can't get to the bus stop?" An equally valid question, however, is "What good is a door-to-door service when the handicapped person gets only as far as a waiting list?" In fact, the disabled person has some control, however slight, over the first situation (i.e., he or she may be able to get someone to help) but has no control over the latter. Actual numbers of people carried is important, of course, but so is potential ridership. Planning services with low saturation points does not solve the transit problems of handicapped people in the long run.

7) Equivalent Availability. To be served, able-bodied users of public transit need only present themselves, at the proper time and place, with the appropriate fare. Visitors to a city use the system without permission. Services for disabled passengers that require advance registration and/or certification by a physician or social service agency exclude a large group of the people they purport to serve. Transportation should never be restricted to members or clients of a particular organization or agency (Cannon, 1976, pg. 4-6).

It is important to note that each piece of legislation and each regulatory phase contains viable concepts which must not be lost. Today's challenge is to extract from each phase what has proven to be valuable and create legislation which embodies these concepts. Transportation legislation should clarify the need for nondiscriminatory transportation services for disabled persons, mandate full access to all new facilities and vehicles, and prescribe criteria for determining equivalence of services for disabled and elderly persons.

C. Paratransit

In many areas special transit systems, commonly known as paratransit systems, have been provided for individuals with disabilities. Paratransit service is generally door-to-door, demand-responsive transportation provided in small, lift-equipped vans. For the most part, transit authorities have used paratransit to attempt to comply with "special efforts" regulations. Its use as the sole mode of accessible transportation reflects the conception that services for disabled people are special and separate from those for the "general public." Transit authorities have commonly used the door-to-door nature of such services to say they are superior to fixed route access.

As currently practiced by the transit industry, "special efforts," now redefined as "local option," have resulted in the design of separate transit systems which provide low levels of service due to demand-limiting restrictions and are therefore highly discriminatory (Cannon & Rainbow, 1980b, pg. 19). These services are almost always restricted and segregated. Restrictions are necessary because such demand-responsive services are very expensive. Since total costs are directly proportional to the total number of trips provided, the number of trips must be limited to keep total costs down. By restricting the number of trips made, some transit authorities have created the impression that paratransit is cheaper than fixed route, accessible bus service. Paratransit appears cheaper only because it meets a small percentage of the actual need.

A General Accounting Office survey showed that many transit systems offer demand-responsive paratransit services to meet "special efforts" regulations. However, because of eligibility criteria and limited resources, 84% of the transit systems reported that they were regularly unable to comply with requests for transportation. One-third of the systems maintained waiting lists of persons needing transit services (GAO, 1982).

In Chicago, for example, the Chicago Transit Authorities (CTA) bus fleet has 2,275 regular buses. All are inaccessible to persons who cannot use steps. The CTA has a paratransit fleet of 42 small buses with lifts for wheelchair users.

The CTA spends over $4 million per year on this paratransit system, which averages about 500 trips per day. Recent actions to contract with an outside provider for these services is expected to increase capacity to provide daily service to 500 additional persons with disabilities, or 1,000 rides per day. This service falls far short of the need: on March 15, 1984, 5,551 persons were certified as eligible for the service, and the Illinois census showed the potential number of transportation-handicapped people in Chicago to be 110,294 (Governor's Task Force, 1985, pg. 10-13).

Ridership is restricted by requiring advanced reservations, individual certification of eligibility for service, establishing waiting lists, and placing restrictions on trip purpose, length and geographical destinations. At an American Public Transit (APTA) workshop in Houston, one transportation provider claimed to have no waiting lists. However, the dispatch office had only two telephone lines which were constantly busy, effectively causing those in need of service to become discouraged and give up (Cannon & Rainbow, Note 18, pg. 23).

Such restrictions deny equal transit services to individuals solely on the basis of handicap, which is prohibited by law. Nondisabled users of public transportation are not subjected to such restrictions. They need only present themselves with the correct fare at the proper place and time to receive service without question. Nevertheless, paratransit systems, with all their limitations and drawbacks, are sometimes the only sensible way to provide service to some disabled and elderly persons. Some specialized services must exist to meet the needs of disabled and elderly persons who cannot effectively use the bus or where the nature of the trip requires door-to-door transportation.

D. Fixed Route Bus Service

Fixed route, lift-equipped bus service provides integrated, accessible service for a large number of mobility impaired people. Appropriate signage and auditory cues make this service more accessible to persons with hearing and visual impairments.

Mainline, accessible bus service has many benefits. Fixed-route access greatly expands the number of potential riders. It provides broader geographical coverage and hours of operation, and more flexibility, reliability and destination options than paratransit alone. This type of access promotes integration, which is essential if people with disabilities are to live independent, productive lives. Fixed-route access is cost-effective, eliminates many of the restrictions imposed by most paratransit systems, and meets a wide range of needs.

Unlike paratransit, as ridership increases on a fixed route, accessible system, the cost per ride goes down. The cost of access is divided by the number of rides taken using those features to obtain perride costs. Currently, the estimated cost of an accessibility package for one bus is not fixed. Estimates fluctuate depending on the size of the order placed by a transit authority and the bus manufacturer's desire to win the bid.

Congressional Budget Office (CBO) reports estimate the costs of each lift at an average of $10,000; the estimate used in a Texas study is $11,000. When challenged, DOT noted the estimated cost of lifts of two lift-equipped bus manufacturers: General Motors, $12,000 (advanced design bus (ADB)); Grumman Flexible, $10,000-$12,000 (in 1980 dollars); and Mitre Corporation, $9,000-$10,000 (in 1979 dollars) (TRB, 1981, pg. 44).

The TRB study also compared the cost of making a bus accessible at the time of purchase ($11,000-$17,000, 1980 dollars) to retrofitting ($20,000-$30,000, 1980 dollars) (TRB, 1981, pg. 44). Savings of about 50% are realized by purchasing accessible buses. Experts estimate the cost of bus access to be about the same in 1985, but many anticipate that increased demand would result in significant price reductions in years to come.

Increased demand and usage should bring solutions to the technical problems transit systems have experienced with bus lifts. The St. Louis, Missouri Bi-State system is often cited as a good example of why bus lift technology does not work. It was the first to obtain wheelchair lifts, and those lifts were the first ones made for commercial use. Since that time, however, lifts have improved dramatically, and have been used with great success in Seattle, Washington; Dayton, Ohio; Champaign/Urbana, Illinois; Johnstown, Pennsylvania, and many other areas.

A strong commitment to preventive and ongoing maintenance is a significant factor in the successful use of lifts. St. Louis Bi-State, according to a National Transportation Journal, quoted in Full Mobility:

> may have been the worst choice for such a first order experiment because, in the words of its own director of engineering, John D. Booth, Bi-State is..."still 20-30 years behind in (its) maintenance program" (Cannon & Rainbow, 1980a, pg. 8).

It is important to note that several studies show that the major maintenance headache of transit operators across the country is actually with air conditioning. According to one study by the Transportation Research Board, air conditioning is more expensive to maintain than lifts. Yet few question the use of Federal funds for the purchase of air conditioning systems, each of which cost approximately $15,000. Air conditioners primarily increase comfort, while expenditures for lifts, which provide necessary access for disabled people, are carefully scrutinized.

VIA, the transit system serving San Antonio, Texas, reported that air-conditioning units alone in the new Advanced Design Buses (ADB's) increased the annual maintenance costs by over 30%. St. Louis found that lifts increased maintenance costs about 5% or $0.01 per bus mile, and reported nonlift repair costs on the same vehicles of $0.10 per bus mile. St. Louis estimated that the Advanced Design Buses (ADB) increased repair costs not covered under warranty by 23%, and total repair costs by 33%.

Los Angeles reports that the maintenance costs per bus for air-conditioning exceeds its per bus costs for wheelchair lifts. Two small California systems reported that wheelchair lifts accounted for less than 5% of all repairs on their ADBs (although lifts account for 6-10% of bus purchase prices). Thus, although there are costs associated with lift maintenance, in general maintenance costs have not increased in proportion to the capital value of the lift (TRB, 1981, pg. 48). Lift maintenance costs must be viewed fairly in comparison with other maintenance costs.

E. Rapid Rail Systems

Accessible rapid rail systems serve persons with different disabilities in a cost effective way. The only substantial cost involved is for elevators; appropriate barrier-free design, for the most part, assures further accessibility without additional cost. An initially high, one-time investment in elevators, coupled with barrier-free design, brings benefits for many years to come. Improved elevator technology will further reduce costs.

Subway systems are made accessible by providing an accessible path from the street through to the platform and onto the train. Elevators frequently provide access from the street to the station and down to the trains. All train cars must be accessible in a way that is coordinated with the station's platforms, i.e., the entrance should be level with the platform. Appropriate signage and auditory cues make the system more accessible to persons with vision and hearing impairments.

The cost of installing elevators in all rapid rail systems have been consistently over estimated. The "321" study conducted by DOT in 1979 of fixed rail accessibility in New York City estimated the cost of making 10 stations accessible as $32.5 million, primarily the cost of relocating sewage and utility lines for existing stations. However, the costs were greatly over estimated. Four years later, the renovation actually cost $9.6 million. Experts believe that an elevator technology commonly used in Europe would reduce the cost of elevators for rail stations by as much as 75%.

In addition, it is incorrect to label elevators solely as an "accessibility feature" of benefit only to disabled persons. In fact they are simply a part of good design since escalators have high accident rates. During an early, one day study conducted in Washington, D.C., Metro counted 64 people in wheel chairs who used elevators. However, 6,000 other people used the elevators for a variety of reasons, such as fear of height, tire easily, leg injury, etc. The variety of problems faced by persons using escalators warrant a viable alternative such as an elevator.

F. Fully Accessible, Multi-Modal Approach

Transit authorities regularly combine various modes of transportation to provide service to the general public. Since disabled people are a part of the general public, these various modes of transportation must be accessible and combined in ways which meet their transportation needs along with those of nondisabled passengers. Fixed-route buses and rapid rail systems must be made fully accessible to provide service to disabled and elderly persons in a manner which promotes integration and independence.

In addition, paratransit service should be available for persons who may be unable to use these systems because of individual health problems or local environmental conditions, and in many rural communities where public transit is limited or nonexistent. Accessible fixed-route bus service and rapid rail systems will free paratransit services for those who need it most. Independent living and mobility training should be made available to assist disabled persons to increase their capacity to use all transportation systems more independently.

A multi-model approach can create a cost-effective transit system that is responsive to a wide range of accessibility requirements and locally identified needs. Fixed route buses with lifts, accessible rapid rail, and auxiliary paratransit door-to-door van service have been combined very successfully in some areas. Cities such as Seattle, Washington, and Champaign/Urbana, Illinois, among others, can be considered models for the development of accessible transportation services in other areas of the country.

1. Champaign/Urbana Mass Transit - Fixed Route Bus Service. Champaign/Urbana, a medium sized midwestern urban area, was chosen as a site for an Urban Mass Transportation Administration-sponsored Service and Methods Demonstration of fully accessible bus service. It has a large population of disabled individuals and a high level of sensitivity to their needs because it is the home of the University of Illinois' Rehabilitation Education

Center. The University of Illinois campus has been accessible for many years and has had an accessible bus service on campus since the early 1950's.

The Champaign/Urbana system has a fleet of 51 buses operated in a grid pattern. The service area is flat. The weather reaches extremes in both summer and winter, and the average winter snowfall is 22 inches.

Extensive planning for accessible service began in 1975, and involved consultation with the Rehabilitation Center and Urban Mass Transportation Administration. The Rehabilitation Center at the University of Illinois advised the Mass Transit District (MTD) that the travel needs of individuals with disabilities were no different from those of the general population; this led them to make all routes accessible rather than concentrating service on certain routes. By retrofitting 15 existing buses and purchasing another 25 new buses with lifts, initial accessibility was achieved. Retrofitting cost $23,00 per bus, while the lifts on the new buses cost only $15,000. An extensive curb cut program in these two cities has greatly added to the success of their transit system.

Before service began, MTD management met with and involved various disability groups. They developed a formal driver training program with assistance from the Rehabilitation Center. MTD's training program included classroom training and hands-on practice operating each type of vehicle. Instead of establishing specific policies on assisting passengers, MTD teaches the operator to be sensitive to each person's needs.

The first accessible buses began operation in 1980. At the end of 1980, one-third of the peak fleet was accessible and the average lift use was 1.7 trips per day. By August, 1984, the fleet of 51 buses was totally accessible. Lift usage increased at that time and is currently used between 15 and 25 trips per day.

Champaign/Urbana also provides a subsidized taxi service for disabled and elderly persons who cannot use the fixed-route buses. MTD subsidizes 50% of the taxi fare. The taxi company operates one lift-equipped van in addition to its regular vehicles (Government Task Force, Urban Institute, 1984, pg. 30-31).

2. Seattle, Washington: Multi-modal Approach to Transit. A model of multi-modal approach is found in Seattle, where the necessary elements of an accessible system have been assembled in a programmatic and cost-effective manner. Seattle's Metro Council decided in 1978 that henceforth all vehicles would be equipped with lifts. This decision was made without reference to 504 regulations. It was a local decision that responded to the needs of the local disabled community and was followed by careful planning. However, this is clearly an exceptional case since it is fairly well known that the major advances toward accessible transportation services for disabled people occurred after "full access" regulations were in place.

A team of elderly and disabled persons, including wheelchair users and transit engineers, travelled around the country to investigate state-of-the-art lift technology. They decided on the Lift-U system, which is being used in other areas of the country with great success. After the system was selected, and several months before the first lift service began, the drivers' union was presented with the proposed policies. A drivers' task force was set up; they acted as a liaison between drivers and management and between drivers and passengers. They identified potential problems and suggested changes to equipment and procedures. After a year, the task force was no longer needed and voted to disband.

After the accessibility decision was made in 1978, Metro inventoried all of its bus zones for needed accessibility improvements, such as curb cuts and culvert covers. They then negotiated with the responsible jurisdictions for street improvements. Along the pilot routes, Metro contracted for the improvements themselves; in some cases Metro matched the local funds for needed improvements. It will be many years before all bus stops are accessible; those that are currently accessible are marked with the international accessibility symbol.

Since 1980, the accessible fleet has climbed from 100 buses on 22 routes to 570 buses on 88 routes. The system is 53% accessible. In 1984, 88,572 one-way lift trips were made over 366 days, for an average of 242 trips per day. Seattle assumes that weekend travel is half of weekday travel, thus these figures imply an average weekday use of 280 one-way lift trips.

Performance of accessible service has not caused time delays; there is no significant difference between accessible and nonaccessible routes. Occasionally, an especially lengthy lift boarding may cause a delay, but the drivers are usually able to make up for such delays with little trouble.

Seattle Metro estimates that its start-up costs were $171,000. Currently their maintenance cost is $355 per bus per year. Operating costs per lift trip was $3.46 in 1984.

In addition to accessible fixed-route service, Metro operates a subsidized taxi program with a 50% subsidy through contracts with two nonprofit agencies. The taxi program is aimed at low income people who are elderly or disabled; 65% of the users are over age 60 and 44.2% have disabilities. Forty-eight percent of the subsidized taxi registrants also use the bus system. In 1985, 7,000 subsidized trips per month were made by taxi. In 1982, Metro's subsidy cost per trip was $2.89, not including Metro's administrative cost. In 1982, Seattle Metro estimated the full cost to be $6.28 per taxi trip, including the passenger's fare.

Seattle Metro also initiated a van program to extend transportation for individuals with disabilities into suburban and rural areas where taxi service is too limited to make the subsidized taxi program viable. Trips are scheduled two to three days in advance. Two nonprofit van agencies provide trips to clients of other agencies as well as people eligible for the Metro Special Transportation Service Program (STSP). In 1983, they provided about 2,200 trips per month to STSP-eligible people, at an operating cost of $4.15 per trip. This cost does not include vehicle depreciation or Metro staff time for monitoring.

Seattle's Metro considers its multi-modal system to be cost-effective. The accessible fixed-route system is relatively inexpensive, allowing more expensive special services to be available to individuals who need that alternative.

Ron Tober, the Director of Transit in Seattle, gave the following explanation of Seattle's success in a recent speech to an APTA Convention (1985):

- Citizens - disabled or not - who knew what they wanted and were willing to support and help us, responded positively.
- Metro's agency-wide commitment - from top management to bus operators and mechanics and all those employees in-between.

Lip service and token efforts fool no one - especially front-line employees. Our management-by-objectives system has many elements relating to lift service. Our salaries are dependent on our meeting these objectives.

- The "political" or community support - from our own Metro Council to other agencies willing to fund curb cuts and improvements enhancing transit service.

- And finally, the decision to make lift service a normal, integral part of our system is probably the single most important key to our success. It is easier to run a system when you know all new buses, not some, will have lifts; when all new operators and mechanics get lift training; and when all information addresses the needs of handicapped peole as a matter of course. We expect success in lift operation as we do in other areas - we do not think of lift service as some special arrangement liable to failure.

- Good management and good planning principles - no different from other areas - have helped make accessible service work in Seattle.

An analysis made by Crain Associates cited these explanations of Seattle's success as the basic criteria necessary to make any transit system successfully accessible. Furthermore, they felt that these criteria could be duplicated anywhere in the country.

Factors such as technology, severe environmental conditions, and expense are common excuses for not making transit systems accessible. Yet many cities, including Seattle, Washington; Champaign/Urbana, Illinois; Dayton, Ohio; Johnstown, Pennsylvania; and Palm Beach, Florida have somehow "miraculously" overcome these "handicapping conditions" to provide successful, accessible transit services to the general public, including disabled and elderly persons in cost-effective ways. Clearly the efforts of these communities should be commended. We must move ahead with appropriate legislation requiring other transit authorities to follow Seattle and Champaign/Urbana's lead in developing multimodel approaches to meeting the transportation needs of transportation-handicapped persons.

G. Cost Issues

Although the cost of eliminating transportation barriers in urban mass transit is very real, the benefits to society may be great. The Congressional Budget Office estimates the potential cost of removing transportation barriers in federally-funded transit systems to be between $4.4 billion and $6.8 billion. These estimates vary according to which of three basic scenarios are being considered to meet the transportation needs of handicapped and elderly people. The first scenario, the transit plan, would cost $6.8 billion over the next 30 years. Of this amount, $2.2 billion would be spent on modifying, operating, and maintaining rail services. This $2.2 billion would also include the cost of providing door-to-door service in lieu of modifying stations and rail cars. The remaining $4.6 billion would be spent on modifying, purchasing, and maintaining transit buses. The second scenario, the taxi plan, would cost an estimated $4.4 billion over the next 30 years. This plan would entail a number of small modifications in existing rail and bus systems. The emphasis, however, would be on providing dial-a-ride vans for handicapped persons. The third scenario, the auto plan, would cost an estimated $6.4 billion over the next 30 years. This plan would provide dial-a-ride service, low-fare taxi services for severely handicapped persons unable to use transit, and financial assistance to purchase specially equipped vans for permanently handicapped people who use wheel chairs. The second and third scenarios would involve ongoing funding, while the first would impose primarily one-time modification costs spread over thirty years (CBO, 1982).

The accuracy of high cost estimates of accessible transportation has been the subject of much controversy. Cost estimates have been criticized as underestimating potential handicapped ridership, overestimating capital and maintenance expenses, miscategorizing capital expenditure costs not included in computing per rider costs for nonhandicapped persons, and inappropriately comparing one-time expenditures with perpetually ongoing expenses of certain transit options. Congressional Budget Office estimates of transportation accessibility costs, for example, have been strongly challenged by the Department of Transportation and are the focus of a book written by Dennis Cannon and Francis Rainbow, two well known experts in this field. The book, "Full Mobility, Counting the Costs of the Alternatives" (Cannon & Rainbow, 1980a) provides an in depth critique of the CBO study, which was heavily dependent on DOT's "National Survey of Transportation of Handicapped People" (also called the Grey Advertising Study).

Cannon and Rainbow express concerns about the conclusions drawn from the data collected by the Grey Advertising Study. They state that "the statistical results of the Grey Advertising Study are not so much in question as are the conclusions derived from them." The conclusions drawn in the study result from a procedure intended to account for "non-commitant survey bias based primarily on assumptions and stereotypes rather than on reality" (Cannon & Rainbow, 1980a, pg. 2). Assumptions were made about the future mobility of disabled persons responding to the survey, based on their identification of barriers which inhibited them from currently using transportation. In fact, the identification of current barriers by disabled respondents eliminated them from being counted as a potential rider. This created the very low estimate of ridership upon which many of the cost figures were calculated.

DOT argued that CBO figures underestimate the numbers of potential handicapped passengers and overestimate maintenance costs, loss of seating capacity, and other expenses. DOT concluded that, based on more realistic figures, the accessible fixed route service is actually less expensive than other alternatives (DOT Congressional Record, June 20, 1980). The American Public Transit Association also expressed concern about attempts to establish national cost estimates, since their own recent attempts to collect cost information on accessible services did not produce credible, accurate, and meaningful cost estimates. Their efforts were confounded by the many factors that influence cost calculations, some of which vary widely. As a result, it is extremely difficult to calculate meaningful estimates.

B.J. Carroll of Seattle's Metro stated that one reason for the difficulty in determining costs of accessible transportation is that the kind and detail of cost analyses conducted in this area are not commonly done for other types of service. For example, when a new bus route is added to an outlying area, ridership at the beginning is low. It takes time for the public to learn about the service, determine if it meets their transportation needs and finally begin using it. The cost per ride per person to provide this service is generally not calculated. If it were, the cost per ride would be extremely high. When a new lift-equipped bus service is started for disabled persons, detailed cost analysis are undertaken to calculate costs per trip or per person. At the start up of new lift-equipped bus service, ridership is low. Thus, costs are high. As with other new bus services, there are start up and ongoing costs, but as ridership increases, costs are reduced.

When ridership is underestimated and related to fixed route-access, the cost per ride becomes inflated because as ridership goes down, costs go up. Thus, when ridership goes up, costs go down. Quite the opposite is true of paratransit. The lower the ridership estimate, the lower the cost of paratransit. As ridership goes up, costs go up because paratransit is labor intensive. Careful analysis of estimated ridership is needed, since the CBO study showed that paratransit is a less costly option. This may be due to low estimates of ridership on fixed-route access.

Whatever the actual costs of accessible transportation, it has clearly significant benefits. Beyond limiting handicapped people's ability to engage in the social, recreational, housing, and educational opportunities available to nonhandicapped people, transportation barriers have a serious negative effect on employment. Transportation is not just a transportation issue--it is an employment and education issue.

According to James Weisman of Eastern Paralyzed Veterans Association of New York, the PVA filed a suit recently against the City of New York for access to transportation. The issue was an attempt to gain access to the work force. In New York City, 80% of the population uses mass transit to get to work. Sixteen percent of the population nationally use public transportation to get to work. Many of these people cannot afford to get around any other way. Many disabled people cannot afford to purchase private vehicles. A quadraplegic purchasing a van needing modifications can expect to spend between $8,000 and $18,000 on modifications alone. A person needs to work for some time before being able to afford such an expensive piece of equipment. With no access to public transportation, they can't get to the job in the first place.

One commentator, Norton Reed, in a study reported in the Transportation Law Journal (1977), has estimated that 13% of unemployment among handicapped people is due to travel barriers and that 200,000 handicapped people would enter the work force if the barriers were eliminated, adding as much as $1 billion in annual earnings to the economy. If this were to happen, disabled people would have returned to society in less than seven years the entire cost of removing transportation barriers as estimated by the CBO.

The Department of Transportation has estimated that approximately $800 million in net benefits to society would result from eliminating transportation barriers. DOT has observed that savings in reductions of Supplemental Security Income costs by increased employment opportunities for handicapped people through accessible transportation would alone account for as much as $276 million annual savings for the Federal Treasury (DOT Regulations, June, 1980, pg. viii-12).

The Department of Transportation states that it is reviewing comments received on its 1983 proposed Section 504 regulations and intends to issue a final rule sometime soon. Significantly, DOT is conducting a cost analysis of the proposed regulations that will be available at the time the final rule is issued.

The bottom line about the cost of making transportation accessible to disabled persons is--no one really knows. National cost estimates remain difficult to calculate as the Department of Transportation and the American Public Transportation Association (APTA) have stated in recent conversations. What we do know is that cost estimates have been both overestimated and underestimated. However, we cannot afford not to invest in accessible transportation. Each year that passes the cost increases and we find ourselves continuing to waste one of our country's greatest resources--disabled people.

III. AIR TRAVEL

The demand for access to air transportation has grown in recent years. Legislation requiring that facilities and buildings receiving Federal financial assistance be accessible has improved physical access to our nation's airports. As access continues to improve and personal and professional opportunities increase, disabled people will travel more. In our highly mobile society, access to the skies is important to a growing number of people.

Though much progress has been made to improve access and eliminate discrimination in the provision of air transportation to disabled people, many problems still exist, including inadequate equipment, untrained personnel, remaining problems with physical access to airports and planes, and outdated rules and regulations. It is not infrequent for disabled travelers to experience the following practical problems when traveling by air:

a) Mishandling, loss or damage to wheel chairs and/or other devices or equipment.

b) Boarding procedures and equipment which are uncomfortable, dangerous and dehumanizing.

c) Inaccessible boarding areas and restrooms in airports and on planes; long distances between terminals, gates and baggage claim areas; and ground transportation which is inaccessible.

d) Patronizing or disrespectful attitudes and treatment by personnel.

A lack of clarity exists regarding which Federal agencies are responsible for enforcement and for responding to and resolving discrimination complaints from disabled consumers.

A. Legislation

The main pieces of legislation related to air transportation are:

- Architectural Barriers Act of 1968
- Section 404 of the Federal Aviation Act
- Section 504 of the Rehabilitation Act of 1973
- Civil Aeronautics Board Sunset Act of 1982.

Each is briefly described below.

1. Architectural Barriers Act of 1968 covers buildings and facilities related to air transportation which are designed, constructed or altered with Federal funds. This has resulted in some improvements in access to our nation's airports. Unfortunately, many airport terminals are not built with Federal funds and are thus not subject to the provisions of this Act. Aircraft are not covered by this Act, meaning that access frequently ends at the jetway.

2. Section 404 of the Federal Aviation Act prohibited discrimination in very broad terms. It was repealed by the Civil Aeronautics Board Sunset Act of 1984. The remaining Section 404A provides for "safe and adequate service." This may be a vehicle for addressing the issue of non-discrimination.

3. Section 504 of the Rehabilitation Act of 1973 prohibits discrimination on the basis of handicap. A recent court decision determined that Section 504 covers all airlines using federally-assisted airports. This means that non-discrimination provisions under this Act require that airlines using federally-financed facilities provide accessible service.

4. Civil Aeronautics Board Sunset Act of 1982 eliminated the Civil Aeronautics Board and formally transferred much of their authority to the Department of Transportation. This was an effort to provide coherence and

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coordination by eliminating overlapping authority. This Act also required the Department of Transportation to consult with the Architectural and Transportation Barriers Compliance Board (ATBCB) before changing policies or regulations affecting air transportation for disabled persons.

B. Current Issues

Section 504 of the Rehabilitation Act of 1973, which prohibits discrimination on the basis of handicap, covers a few small air carriers which receive direct federally subsidies. These carriers provide only a small percentage of our nation's air transportation. Therefore, to achieve meaningful access to the skies, larger commercial aircraft must also be prohibited from discriminatory policies and practices.

Currently, the Department of Transportation's (DOT) authority over larger air carriers that are not directly federally subsidized but that use federally-assisted airports is uncertain. A Section 504 suit involving the Paralyzed Veterans Administration (PVA) and the Civil Aeronautics Board (CAB) examined the coverage of nonfederally-assisted airlines under Section 504 of the Rehabilitation Act of 1973. This case resulted in a decision which states that airlines using federally-assisted airports are covered by the non-discrimination provisions of Section 504 (PVA vs. CAB, 1985). The Justice Department is appealing this decision. The Supreme Court has recently agreed to hear the appeal.

Explicit legislative prohibitions are needed against discrimination on the basis of disability in air transportation. Regulations implementing the provisions of such a law should be based on sound knowledge and well-researched information about the needs of disabled people and the safety in transporting them. Some aspects of current regulations seem to reflect inaccurate assumptions about the abilities and inabilities of disabled travelers. The Council believes that a significant research effort is needed to determine the most comfortable, safe and effective way to provide accessible air transportation for people with disabilities.

Equal access to air transportation requires the appropriate combination of tangible structural changes, appropriate signage, safe equipment and trained personnel. Equal access requires:

- Structural modifications to make restrooms, airports, and aircraft accessible.
- Increased and improved signage, including Braille.
- Purchase of equipment such as Telephone Devices for the Deaf (TDD's) to facilitate communication.
- Improved equipment such as boarding chairs and wheel chairs.
- Training programs for personnel involved in transporting disabled passengers.

Such changes will probably require at least some Federal financial support.

Standards and minimum guidelines should be developed by the Department of Transportation (DOT) and the Architectural Transportation Barriers Compliance Board (ATBCB). Neither DOT nor ATBCB are authorized by the Architectural Barriers Act of 1968 to establish standards and guidelines for accessible air transportation. If such standards and guidelines were in place, air transportation system developed with or benefitting from Federal funds would in fact be required to offer accessible air transportation.

IV. INTERCITY, INTERSTATE BUS

Although many persons with disabilities live in rural areas, no recent transit study deals in a significant way with their transportation problems. Often the intercity bus transports nondisabled persons living outside major transit service areas to and from the major cities. Many rural residents rely on the bus to get to work and to reach the essential services and opportunities available only in the city. However, most intercity coach buses do not have lifts or other access features to make them usable by disabled people who use wheelchairs.

Bus companies like Greyhound, Trailways, and other similar carriers are under no Federal requirements not to discriminate against disabled people. They are not covered by Section 504 of the Rehabilitation Act because it does not cover interstate commerce. Because they receive no Federal financial assistance, laws governing recipients of funds from a Federal granting authority do not apply.

The American Bus Association does have an informal policy which allows disabled persons to travel with an attendant who rides free. The policy also allows for transporting guide dogs. Some companies--Peter Pan, for example--equipped buses with lifts but discontinued their use, apparently due to low ridership and technological problems related to the lift. The low ridership may have been due to a lack of outreach and advertising of their services.

Two companies, Eagle and Neoplan, have developed a lift which apparently remedies some of the technical problems of the lifts for coach buses. However, there is little incentive for these companies to purchase and operate these lift equipped buses since there is no legal requirement and the demand has been low, at least from their perspective.

V. AMTRAK

Amtrak is a federally-funded, intercity, interstate transportation system that provided transportation to over 19,983,000 people in 1984. The number of disabled people who ride Amtrak is unknown. According to the Department of Transportation, Amtrak's general ridership is down nationally, and substantial cutbacks are expected in the near future.

Amtrak is covered by Section 504 of the Rehabilitation Act, which prohibits nondiscrimination on the basis of handicap. In addition, Amtrak trains are required to have at least one car in which the food car is accessible. Amtrak's terminals are covered by the Architectural Barriers Act of 1968.

Amtrak is also covered by the Amtrak Improvement Act of 1974, as amended in 1976, which states:

> The Corporation is authorized to take all steps necessary to insure that no elderly or handicapped individual is denied intercity transportation on any passenger train operated by or on behalf of the Corporation, including but not limited to, acquiring special equipment and devices and conducting special training for employees; designing and acquiring new equipment and facilities and eliminating architectural and other barriers in existing equipment and facilities to comply with the highest standards for the design, construction, and alteration of property for the accommodation of elderly and handicapped individuals; and providing special assistance while boarding and alighting and in terminal areas to elderly and handicapped individuals.

This Act has been criticized for not actually mandating nondiscrimination. Regardless, Amtrak has undertaken the writing of a transition plan to achieve access to their facilities and trains. This transition plan is a massive four volume document outlining substantial plans for achieving access. Unfortunately, cutbacks in funding have significantly affected Amtrak's ability to move forward with the plan. Since expenditures for capital improvements have virtually been eliminated, access has been difficult to achieve.

The National Council on the Handicapped commends Amtrak for its efforts and recommends that improvements in access continue as capital expenditures become more available.

VI. PRIVATE TRANSPORTATION

An accessible private vehicle is often an important key to independence for a person with a disability. People with disabilities make about 72% of their journeys by private auto. Many depend on others to drive them. While 16% of the daily journeys made by able-bodied persons are made as passengers in private cars, the corresponding share for persons with disabilities is twice as large--34% (DOT UMTA, 1978). Due to the continuing lack of adequate accessible public transportation, disabled people often must rely on private transportation. However, persons with disabilities are less likely to own a car and to be licensed to drive than nondisabled persons.

In many rural areas where there is little or no public transportation, a car or van may be the only way a disabled person can achieve some level of mobility. Since isolation is one of the most devastating and debilitating conditions which rural disabled people face, access to transportation can greatly increase their participation in a variety of community activities and enable them to seek employment. In a rural area even a short trip to the store for a carton of milk requires the use of a car. Without an adapted automobile or van, employment, which is usually available only in major activity centers many miles away, can be an impossible goal.

Many disabled persons in rural areas live with their families and are totally dependent on them for transportation and thus life support. This condition perpetuates isolation and places a heavy burden on the family. The problem is particularly severe when a severely disabled person who uses an electric wheelchair requires an accessible van with a lift.

The low income associated with disability in both rural and urban areas often prevents disabled individuals or their families from purchasing the type of vehicle needed and/or from making the modifications required to make a vehicle accessible. Disabled people's lack of adequate resources is documented in studies of the transporation-handicapped population. As a group, disabled people tend to be older than the general public and are more likely to be unemployed. They are likely to have low incomes; 34% of the households of persons with transportation handicaps have incomes less than $4,000. This is more than double the rate for the total urban population (DOT/UMTA, 1979). Thus, they need assistance with the purchase and modification of vehicles.

Modifications to private vehicles can be expensive. The current cost of hand controls installed in a car is about $400. Van modification costs are much higher, ranging from $2,000 for adaptions to enable a disabled person to be a passenger to from $5,000 to $18,000 for disabled drivers. Such costs are prohibitive for people on fixed or modest incomes.

Access to and the availability of driver training is another important issue. Most training schools do not have accessible vehicles with which to train disabled persons. Some schools that do offer accessible vehicles charge higher rates to their disabled customers to cover the costs of vehicle modification and instructor training. Some rehabilitation centers offer both driver evaluation and training, but frequently serve only clients of the State vocational rehabilitation department. Sometimes there is only one such facility available in a State. For example, in Massachusetts there is only one location where rehabilitation clients with severe disabilities can go for evaluation and training. This means that some persons have to travel three hours or more to get to the rehabilitation center. This distance makes it impossible for most people to use this facility for driver training. Larger States have even greater problems in this respect.

Licensing of disabled people is also a concern. Laws vary from State to State as to who can and cannot drive. For instance, a person with epilepsy must be free of seizures for varying lengths of time, depending on the State. As a result, a person who can legally drive in one State may not be able to drive in a neighboring State.

State rehabilitation agencies have successfully provided driver evaluation, training, and vehicle modification programs for years. They should be encouraged and assisted to expand these services for disabled persons needing this assistance. Funding for these programs should be continued and increased where appropriate and needed.

The Council also recommends that accessible driver training be incorporated where appropriate into the public schools and designated in individual educational plans. This training should also be made available through adult and continuing education programs. Partnerships should be encouraged between the auto industry and driver training schools so that accessible vehicles can be obtained for training. Because driver training is often limited for disabled persons who require modified vehicles, such cooperation should greatly expand opportunities for driver training for disabled persons. The benefits would be especially great for disabled persons who are not clients of State vocational rehabilitation or who live far from rehabilitation facilities providing training and evaluation.

Currently, States vary in the standards and methods they use in determining ability to drive. Some of this may be discriminatory in nature.

Realistic criteria must be developed and should be applied equitably and commonly by all States. States with licensing practices which have proven effective and nondiscriminatory should be used as models by other States for developing standards for assessing driving ability.

An additional problem is that of defining a disabled person for the purpose of issuing a special license plate or placard to allow parking in spaces designated for disabled persons. Some clarification is needed to insure equal treatment from State to State. Disabled plates or placards should be valid for use in any State. For example, "disabled" plates from Arizona should be honored in California and in every other State. The Paralyzed Veterans of America have developed model regulations for the parking and licensing of motor vehicles used by handicapped persons. These model regulations should be considered, with modification as appropriate, for incorporation into Federal and State legislation addressing these problems.

VII. NATIONAL POLICY PRINCIPLES FOR ACCESSIBLE TRANSPORTATION

Our national policy for meeting the transportation needs of disabled persons must have as its foundation the following principles:

1. The needs of disabled and elderly people should be considered within the range of needs of the general public.

2. Affirmative efforts must be made to alleviate institutionalized discrimination in transportation. Discrimination in public transportation, whether intentional or unintentional, is intolerable in our highly mobile society.

3. Integration of disabled and elderly persons into the mainstream of society is of the utmost importance to maximize the potential for independence and productivity. Thus, segregation based on anything other than individual need is unacceptable.

4. The individual needs of disabled and elderly people vary with the severity of disability and/or environmental circumstances. Thus, transit options must be available which respond to a wide range of needs.

5. Eventually full access to public transportation must be achieved. Thus, all new facilities and vehicles must be accessible. Retrofitting and renovation should be done to make existing facilities and vehicles accessible and usable where new construction or purchase of vehicles is not imminent.

6. Disabled and elderly persons have a right to the same level and quality of service as is provided to nondisabled persons, including:

    Service Range
    Transfer Frequency
    Fare
    Travel Purpose
    Trip Decision/Travel Time
    Capacity
    Availability

7. Disabled and elderly consumers must be actively involved in substantial and meaningful ways in the planning, development and evaluation of transportation policies and programs.

8. Investing in accessible transportation is a cost-effective way to maximize the benefits of investments made in other areas such as education, rehabilitation and employment.

VIII. RECOMMENDATIONS

A refusal to invest in public transportation is a refusal to face the realities of the future. This year alone 250,000-300,000 young adults will graduate from special education. Many of those students will seek employment and additional educational experiences. If transportation is unavailable to them, money invested in their education is for the most part wasted. Disabled people who are educated will not settle for idle and unproductive lives. We can anticipate that their independence will be far greater than that of many disabled adults today, some of whom have had little opportunity for education or have grown up in isolated and segregated surroundings. More and more disabled students are graduating from college each year. They have the right and obligation to become employed when they finish school. Society cannot afford to waste this valuable resource because of the absence of accessible transportation.

In 1984 a disability policy statement was developed by the National Council on the Handicapped and approved by the President. It calls for full integration, improved access, and increased opportunity for disabled people. In accordance with this policy, the National Council believes that the recommendations that follow should be established in the area of transportation.

The following recommendations are made by the Council as a first step in the development over time of fully accessible transportation systems nationwide.

Urban Mass Transit

1. Congress should amend Section 16 of the Urban Mass Transit Act to require full accessibility to mass transportation to be achieved over a realistic period of time: Such amendments should:

   a. Prohibit discrimination on the basis of disability by recipients of Federal funds under this Act.

   b. Require recipients to provide a level of service to disabled and elderly persons that is equivalent with that available to nondisabled persons in terms of: 1) service range, 2) transfer frequency, 3) fare, 4) travel purpose, 5) trip decision/travel time, 6) capacity, and 7) availability.

   c. Require that all new facilities and vehicles constructed or purchased with funds under this Act be accessible.

   d. Require recipients of funds under this Act to develop specific transition plans for achieving, within a reasonable period of time, full access and comparable service levels. These plans should be developed with the substantial and meaningful involvement of disabled and elderly consumers.

   e. Create a private right of action for persons who believe they have been discriminated against by recipients under this Act.

Full access to transportation can only be accomplished by combining various modes of accessible transportation, including fixed route buses, specialized services, and rapid rail systems. Such a system can provide to disabled and elderly persons reliable transportation services that are tailored to local conditions, accessible, and equivalent in the quality and level of service to that provided to other citizens. All new facilities and vehicles should be required to be accessible. By making facilities and vehicles accessible at the time of construction or purchase, unnecessary, expensive retrofitting and renovation can be avoided. Disabled and elderly consumers must be involved in substantial and meaninful ways throughout the process of planning, implementing, and evaluating transit systems.

The Council also believes that persons who feel that they have been discriminated against in the provision of transportation should have individual and collective recourse for resolution of their rights through the courts. The potential for court action would also provide a clear incentive to transit authorities to act in nondiscriminatory ways so as to avoid sanctions which might be imposed by a court of law.

2. Congress should amend the Architectural Barriers Act of 1968 to establish the Department of Transportation as a standard-setting agency for the development of access standards for buildings, facilities, and public conveyances, including rolling stock and aircraft, which are designed, altered, constructed or purchased with Federal funds to insure that they are readily accessible and usable by disabled and elderly persons.

The Department of Transportation (DOT) currently sets transportation standards governing such matters as configurations of vehicles, communication access, appropriate signage, and safety. This recommendation will clearly establish DOT as the standard-setting agency for accessible transportation under the Architectural Barriers Act. The required standards would set forth specific requirements to guide transit authorities in designing accessible transit systems and evaluating their effectiveness.

Section 502(B) of the Rehabilitation Act of 1973 directs the Architectural and Transportation Barriers Board (ATBCB) to set minimum guidelines and requirements for standards developed by the standard-setting agencies under the Architectural Barriers Act. The combination of setting standards and establishing minimum guidelines and requirements will provide greater assurance to disabled and elderly persons that transportation systems developed with Federal funds will in fact have access features which make them usable in a meaningful way.

It should be noted that certain technical changes to the initial text of the Architectural Barriers Act would be needed to accommodate the addition of DOT. Thus, coverage of "public conveyances" and things which are "purchased" with Federal funds should be added.

Air Transportation

3. Congress should amend the Federal Aviation Act to:
    a. Prohibit discrimination on the basis of disability by all airlines using federally-assisted airports.
    b. State that airlines using federally-assisted airports are subject to the provisions of Section 504 of the Rehabilitation Act of 1973 and regulations promulgated thereunder.

Currently only a few small air carriers are directly federally subsidized and thus covered by nondiscrimination provisions under Section 504 of the Rehabilitation Act of 1973. These air carriers provide only a small percentage of this nation's air transportation. To assure accessible air transportation for America's disabled and elderly citizens, Congress should require that all airlines using federally-assisted airports be prohibited from discriminatory practices and subject to regulations promulgated under Section 504. Airlines should also be required to review and eliminate current practices and policies which have resulted in discriminatory, ineffective, and often dangerous service to disabled and elderly persons. Recommendation 2 above, requiring the Department of Transportation and the Architectural and Transportation Barriers Compliance Board to set standards and minimum guidelines for access, covers the provision of air transportation. This will insure accessible airports and aircraft.

4. Congress should extend coverage of handicap nondiscrimination requirements to interstate commerce, thus prohibiting such discrimination by intercity and interstate bus companies.

Intercity and interstate bus transportation is often the only form of public transportation connecting people in rural areas with major cities and towns. By prohibiting discrimination and improving access to this type of transportation, many more people would be able to take advantage of the many educational, recreational and employment opportunities found only in the city. (For further discussion of nondiscrimination provisions, see the paper on "Equal Opportunity Laws.")

Private Transportation

5. Congress should establish a low-interest loan program based on income to assist disabled persons and families with disabled children or elderly persons to purchase vehicles or to make necessary access modifications.

Private transportation provides the only means by which many disabled and elderly persons can become employed and participate in educational and recreational programs. In rural areas, private transportation is frequently the only transportation option. Since the cost of purchasing and modifying vehicles is prohibitive for many disabled persons and their families, such a low-interest loan program is needed to supplement the other transportation options outlined above. Federal funding for such a program should be provided up to a reasonable cap amount as established by Congress.

6. Congress should direct the Department of Transportation to commission a study, based upon its existing authorities and targeting currently available funds, to assess the impact of increased access to transportation on employment, education, and quality of life for disabled and elderly persons.

Little current data is available to document the potentially great benefits resulting from accessible transportation. Older studies suggest many benefits, both economically and in terms of life equality, that are associated with access to transportation. The study called for in this recommendation would provide more up-to-date documentation of such individual and societal benefits.

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TOPIC PAPER F:

HOUSING

National Council on the Handicapped

February, 1986

ACKNOWLEDGMENT

This is one of a series of ten topic papers developed by the National Council on the Handicapped as part of its Special Report to the President and Congress: TOWARD INDEPENDENCE: An Assessment of Federal Laws and Programs Affecting Persons with Disabilities--With Legislative Recommendations. The members of the National Council on the Handicapped wish to expressly acknowledge with appreciation the special contribution made to this paper by Robert L. Burgdorf Jr. and Janet Anderson.

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I. OVERVIEW

Housing is a fundamental requirement for living independently. An acute lack of housing opportunities for persons with disabilities severely impedes the social integration and independence of disabled Americans. The shortage of appropriate housing options, long apparent to many handicapped individuals, service agencies, and professionals, was recognized by the White House Conference on Handicapped Individuals in 1977 and has been documented in the few formal studies of the subject. A 1981 report of the United States General Accounting Office observed:

> Although no reliable statistics exist on the number of accessible housing units in the United States, officials of the Departments of Education, HHS, HUD, and some national organizations serving people with handicaps told GAO that accessible units are in short supply.
> (GAO, 1981)

Housing Needs of the Handicapped, a March 1982 report of the Department of Housing and Urban Development (HUD), initiated at the direction of the U.S. Congress, acknowledged the unmet housing needs of people with disabilities and concluded that the extent of such needs had not yet even been assessed, much less addressed (HUD, 1982).

HUD is currently pursuing a number of initiatives to redirect the focus of Federal housing programs. This paper suggests means by which the redirection of Federal housing programs affecting people with disabilities may be most effectively accomplished. In addition, the paper offers suggestions for the expansion and improvement of laws guaranteeing fair and equal housing opportunities for persons with disabilities. President Reagan has endorsed the concept of extending the coverage of housing nondiscrimination laws to protect persons with disabilities, and has indicated that such expanded coverage is supported by "a clear consensus of the Congress" (President Reagan, 1983, p. 992).

Federal housing programs and laws which assure equal access to housing reflect a far-sighted, astute use of Federal resources, because they help to avoid the costly institutionalization of persons with disabilities. Available data (to be discussed in part IV of this paper) suggest that the costs of providing appropriate housing options for people with disabilities are not substantial when compared to the significant savings engendered by enabling individuals with disabilities to live in the community, get jobs, and pay taxes.

II. FEDERAL HOUSING ASSISTANCE AND LOAN PROGRAMS

The Federal Government has played a major role in seeking to provide adequate housing for elderly people and individuals with disabilities since 1959, when Section 202 of the Housing Act of 1959 was enacted. Today, an amended version of Section 202 is the only Federal housing legislation that explicitly mentions persons with disabilities as a targeted class for housing opportunities. Certain other Federal housing programs, however, including the traditional Section 8 Program, the Administration's housing voucher program, and community development block grants, have been used to provide additional housing options for persons with disabilities, even though disabled persons are not expressly mentioned in the statutes authorizing these programs.

A. Section 202

Section 202 of the Housing Act of 1959 authorized direct, low-interest loans for housing for elderly persons. In 1964, Section 202 was amended to include handicapped persons and their families. From 1959 until it was temporarily phased out in favor of other programs, this direct loan program provided construction financing and 50-year permanent loans at 3 percent interest to nonprofit and limited-dividend sponsors of housing for low and moderate income elderly people. The program prompted the construction of over 45,000 units in its 10 years of operation. This early Section 202 program was considered to be a great financial success -- only one of approximately each 30 loans had to be foreclosed. It was also a popular program among elderly people. The program was phased out, however, largely in favor of construction financed by the Section 236 program, another HUD mortgage subsidy program.

The Housing and Community Development Act of 1974 (P.L. 93-383) amended the Section 202 program to permit construction loans and direct 40-year permanent financing to nonprofit sponsors for the construction or substantial rehabilitation of housing projects for elderly or disabled persons. As further amended in 1976, the loans were made at a rate based on the average interest rate of all interest-bearing obligations of the United States which form a part of the public debt, plus an amount to cover administrative costs. The Secretary of HUD was authorized to borrow funds for this program from the Treasury Department, where a revolving loan fund for housing of elderly and disabled persons had been established.

An important aspect of the revised Section 202 program was the requirement that all projects receiving the long-term loans must qualify for, and would receive the benefits of, leased housing assistance payments under the Section 8 program (to be discussed below). This means that eligible tenants would not pay more than 25 percent of their incomes for rent, and that developers would be virtually assured a pool of federally subsidized tenants. To guarantee the availability of such funding, reservations of Section 8 funds were set aside at the time that Section 202 funds were reserved for a project.

The Housing and Community Development Act was signed into law in 1974, but final regulations for the Section 202 program were not issued until February 25, 1976. Potential sponsors, including small nonprofit community groups and churches, claimed it would be extremely difficult to obtain long-term financing due to the special provisions of the leasing program. At that time, HUD Section 8 housing assistance payments for tenants were provided for a period not exceeding 20 years whenever private financing was used. Under these circumstances, financial institutions were wary of offering 40-year financing. An alternative would have been Federal Housing Administration (FHA) multi-family insurance, but some housing sponsors pointed out that even if FHA insurance were obtained and long-term financing located, points charged by lenders would have priced many nonprofit organizations out of the market. Strong opposition from these potential sponsors led to a Congressional mandate that HUD rescind the initial regulations and implement the program in a manner that would assure permanent financing.

The record of the original Section 202 program provides a useful backdrop against which to assess the progress and accomplishments of the revised program. The original program appears basically to have served a middle income group of elderly persons with yearly incomes at that time of $5,000 to $7,000. No asset limits were imposed. The revised program serves persons with a wider range of incomes, since it is used in conjunction with the Section 8 program, which is currently HUD's major vehicle for providing housing to low-income households. Eligible households are those with incomes under 80 percent of the median in their area, adjusted for family size. Higher income households may live in such projects if they pay market rate rent.

As of December 31, 1984, there were approximately 2,257 Section 202 projects nationwide, with 142,120 occupied housing units. In 1985, $600 million was appropriated for 12,000 additional units of Section 202 housing. Beginning in 1986, as part of the President's spending freeze aimed at reducing the Federal budget deficit, his budget proposes a 2-year moratorium on new assisted housing production. As a result, no new funding for Section 202 has been recommended in the budget, with the exception of a $50 million loan limitation to support approved projects already in the pipeline.

HUD has also begun the selling of Section 202 mortgages to private sector buyers, with the understanding that the investor continue to offer low-cost housing services that meet Section 202 regulations and guidelines to elderly and disabled people. In addition, the investor must continue Section 8 certificates to tenants as under the Section 202 program.

The administration of the Section 202 program has engendered some problems. Approval of Section 202 loans has sometimes involved long delays. One reported incident concerned a Fairfax, Virginia group that waited for more than two years for approval of a loan application for a housing unit for disabled persons (Specter, M., _Wasington Post_, April 15, 1985). The Section 202 application and approval procedures, primarily developed with large high-rise projects in mind, have proven inadequate and cumbersome as applied to smaller housing alternatives such as group homes for people with disabilities.

In its Section 202 Handbooks, HUD has imposed upon Section

202 borrowers a requirement that they must provide a "support service" component designed to meet the "special needs" of the clientele they propose to serve. Although intended as a protection for handicapped residents of Section 202 programs, the support service requirement has become an eligibility restriction, allowing developers to refuse to rent to any disabled person who does not have the specified disabling condition. In a New York case, two developmentally disabled persons were denied admission to a Section 202 program that had been established for elderly and mobility impaired persons, even though they argued that they were capable of living independently and needed no special services from the housing facility (Brecker v. Queens B'nai B'rith Housing Dev. Fund, 607 F.Supp. 428 (E.D.N.Y. 1985)). Similarly, in a New Jersey lawsuit, mentally ill persons complained that they had been denied admittance to a Section 202 program because of their disability (Edge v. Pierce, 540 F.Supp. 1300 (D.N.J. 1982). HUD has supported the approach of housing developers who argue that they may refuse admittance to all disabled people who are not members of the targeted groups (Ratner, 1985).

The HUD Section 202 Handbook sets unit limits in the development of housing for chronically mentally disabled persons. HUD calls for projects that are designed exclusively for chronically mentally ill individuals and may provide group homes for up to 15 to 20 people. In addition, HUD policy requires that both group homes or independent living residences must be on scattered sites, and specifies that shared living arrangements require a variety of support or assistance that may take the form of resident house parents, supervisors, attendants, or live-in aides. Such support services or assistance may be funded under Title XX of the Social Security Act. The listing of such support assistance for mentally disabled persons in the Section 202 Handbook evidences a HUD expectation that such persons not be housed in HUD-funded projects other than those projects targeted for their specific disabilities.

While disability specific housing may be motivated by good intentions to secure support services necessary to permit persons with certain disabilities to live together in HUD-funded projects, the overall impact of Section 202 programs is often contrary to concepts of integrated and independent living for individuals with disabilities. Many Section 202 projects serve to isolate younger persons with disabilities from other persons of the same age, as placement is often in housing developments that are otherwise only for elderly people. And disability specific housing often means the segregation of all people with disabilities in a particular wing or building.

Disability specific programs may sometimes serve legitimate purposes as a means of partial community integration for certain people with disabilities who require support programs or supervision. Such housing should be an option for people with disabilities who wish to reside together in the same project, building, or wing. But apart from such personal choices and programmatic requirements, many people with disabilities are unnecessarily segregated from their nondisabled peers, and do not become socially integrated in their communities as a result of being a tenant in a Section 202 housing unit.

B. Section 8 -- Lower Income Rental Assistance

1. The Traditional Section 8 Programs. Section 8 of the U.S. Housing Act of 1937 (42 U.S.C. 1437f) created a program to aid low and very low income families, including persons with disabilities, to obtain decent, safe, and sanitary housing in both private accommodations and Section 202 housing projects. Section 8 contains a requirement that HUD make up the difference between what a low or very low income household can afford and the fair market rent for an adequate housing unit. Eligible tenants must pay the highest of: 30 percent of adjusted income, 10 percent of gross income, or the portion of welfare assistance designated to meet housing costs. Housing subsidized by HUD under Section 8 must meet certain standards of safety and sanitation, and rents must fall within a range of fair market rents as determined by HUD.

Traditionally, Section 8 assistance was made available through several different HUD programs addressing various types of housing development. The Section 8 Existing Housing (Certificate) Program was applicable to provide rental assistance for tenants in existing housing. The Section 8 New Construction or Substantial Rehabilitation Housing Assistance Program provided rental assistance for newly constructed or rehabilitated housing. Although the Section 8 program is still available to existing Section 202 and non-202 housing, this type of rental assistance is currently not being provided for new Section 202 construction or substantial rehabilitation projects. By the end of Fiscal Year 1983, a total of 1,760,216 housing units were receiving subsidies under the Section 8 program (Programs of HUD, 1984). The average Section 8 certificate in 1985 was $7,121 per unit in a Section 202 project.

2. The Voucher Program. The Housing Voucher Demonstration Program is a demonstration or pilot project that provides low to very low income individuals or families, including people with disabilities, an income supplement for housing. It allows assisted families or individuals to seek housing in the open market. Congress authorized this demonstration project in 1983 in Section 207 of the Housing and Urban-Rural Recovery Act of 1983 (Public Law No. 98-181).

The voucher program modifies and builds on the Section 8 Existing Housing Program. Both programs utilize the existing housing stock already available in a community, thus sheltering a greater number of tenants on a less costly basis than new construction programs. The free market characteristics of the programs allow tenants a greater choice of units and communities, and furthers individual selection in avoiding social and racial segregation. Vouchers and certificates can serve to open a greater portion of the community to low income residency.

The voucher program is basically straightforward:

- The voucher is issued by a local public housing authority to a family or an individual eligible for housing assistance.
- The voucher allows the family or person with a disability to shop for decent, safe, and sanitary rental housing and guarantees payment to the landlord of a portion of the rent.

- o HUD pays the difference between 30 percent of a family's adjusted gross income and a reasonable rent level for a given area.
- o The subsidized family or person with a disability has an additional "shopping incentive" that allows it to balance cash resources with housing goals. The family may rent below the payment standard (set at the 45th percentile of an area's median rents) and pocket the savings, or it is free to spend more if it so chooses.

The voucher program appears to be less costly than some previous approaches. In Fiscal Year 1982, the Federal Government provided $4.9 billion in Section 8 New Construction budget authority to subsidize families in 33,000 low-income housing units. It is estimated that the same amount of budget authority would have provided 325,000 households with assistance through vouchers. Based on this comparison, the voucher subsidy appears nearly 10 times as effective than the Section 8 New Construction Program on a purely numerical basis. The contrast is even more dramatic when one focuses on households identified as "worst case" families with the most need for housing assistance. The 33,000 units developed under the New Construction Program can serve only 4 percent of the "worst case" families, and the aid only arrives after a 12-month to 24-month construction period. On paper, vouchers could have aided 40 percent of the "worst case" families, and would have provided assistance much more quickly than by building new units.

3. Improving Rental Assistance Programs. Neither the traditional Section 8 Programs nor the newer Voucher Program is a total panacea; each can and should be improved to provide more effective housing assistance to low income families, especially

those having family members with disabilities. To guarantee that housing assistance flows to individuals and families with the greatest need, HUD has directed that most future assistance be targeted to families with incomes at or below 50 percent of an area's median income. In addition, the Department has made a special effort to target housing assistance to households that have had particular difficulty in participating in HUD's programs in the past. Large families and people with disabilities traditionally have had difficulty in locating units appropriate for their needs. HUD has adjusted its fair market rents for its Section 8 Existing Housing Program to allow higher rents for apartments with three or more bedrooms. Higher rents should motivate some owners of large units to participate in the Section 8 Existing Housing Program. In addition, a new Rental Rehabilitation Program and a Housing Development Grant Program will assign a high priority of funding projects that contain units with a large number of bedrooms (The President's National Urban Policy Report, 1984).

The effectiveness of rental assistance programs is largely dependent upon the degree to which they reflect a realistic appraisal of the rental housing market. Some landlords will not accept tenants who are dependent upon public housing assistance. In areas where there is an insufficient supply of adequate housing at affordable prices, the monetary level of rental subsidies under Section 8 Existing Housing and Vouchers Programs may force recipients to reside in substandard, inappropriate units. This problem is all the more severe for individuals with disabilities who need to find housing that is both affordable and accessible. Neither the Vouchers Program nor the Section 8 Certificate Program is a cure for an absence of suitable units in a community. Consequently, some form of a Section 202 or similar housing construction program is necessary to promote the development of additional housing units suitable for indiviuals with disabilities. Moreover, rent subsidies must be set at realistic levels that permit recipients with disabilities to obtain adequate units. Determinations of fair market rents for subsidized housing should take into account cost differentials resulting from special needs of some individuals with disabilities, such as the housing of a person's attendant, particular accessibility requirements, and the desirability of group living arrangements for some persons with disabilities.

C. Community Development Block Grants

The Community Development Block Grant (CDBG) Program provides community and economic development support to cities, counties, Indian tribes, and U.S. territories. The block grant format of the program allows States and localities discretion to choose how to allocate CDBG funds to supplement other available resources. The Administration has emphasized increased local discretion and modifications of the program designed to permit greater use of economic development and private sector involvement.

The largest portion of the CDBG program involves entitlement grants. The entitlement program provides annual grants on a formula basis to entitled communities to carry out a wide range of community development activities directed toward neighborhood revitalization, economic development, and improved community facilities and services. Entitlement communities develop their own programs and funding priorities and consult with local residents before making final decisions.

All CDBG activities must either benefit low- and moderate-income persons, aid in the prevention or elimination of slums and blight, or address other community development needs that present a serious and immediate threat to the health and welfare of the community. Some of the activities that can be carried out with community development funds include the acquisition of real property; rehabilitation of residential and nonresidential properties; provision of public facilities and improvements, such as water and sewer, businesses to help with economic development activities.

No less than 51 percent of the funds must be used for activities which benefit low- and moderate-income persons, over a period specified by the grantee, but not to exceed three years.

Metropolitan cities and urban counties are entitled to receive annual grants. Metropolitan cities are central cities of Metropolitan Statistical Areas (MSAs) or other cities within MSAs which have populations of at least 50,000. Urban counties are counties located within MSAs which are authorized to undertake community development and housing activities and which meet certain population requirements.

Another CDBG program provides non-entitlement grants for States and small cities to carry out a wide range of community development activities directed toward neighborhood revitalization, economic development, and improved community facilities and services. Applicants must give maximum feasible priority to activities which will benefit low- and moderate-income families, aid in the prevention or elimination of slums and blight, or address other community development needs that present a serious and immediate threat to the health or welfare of the community. No less than 51 percent of the funds must be used for activities which benefit low- and moderate-income persons over a period specified by the State, but not to exceed three years.

Under 1981 amendments to the CDBG legislation, each State has the option to administer the block grant funds provided for its non-entitlement areas. If this option is exercised, the block grant funds are provided to a State, and it distributes them as grants to eligible units of local government. A State's objectives and methods of distributing the funds are determined in consultation with affected citizens and local elected officials, and must be made available to citizens and units of general local government throughout the State. States are required to report annually on the use of such funds. If the State's option is not exercised, HUD serves as administrator and awards funds in a competition on the basis of selection criteria established by the Department.

$3,468,000 were appropriated for Community Development Block Grants in 1984. For 1985, the estimated figure is $3,472,000. The Administration's proposed budget for 1986 would involve a 10 percent cut in the CDBG program to $3,124,800. Long-range projections would see the program rise to $3,277,900 in 1987;

$3,412,300 in 1988; $3,548,800 in 1989; and $3,680,100 in 1990.

The CDBG program does not explicitly target or mention projects for people with disabilities. But many communities have used CDBG funds for disability-related projects. One noteworthy example is Baltimore County, Maryland, where the County Executive has earmarked 20 percent of CDBG funds for projects to benefit individuals with disabilities. Such funding is provided to grantees by the County in conjunction with the Baltimore County Coalition for Handicapped Persons. Approximately $5 million of CDBG funds have been spent by the County over a four year period for such projects as small residential alternatives for people with disabilities and the removal of architectural barriers. In developing residential alternatives, the County has made relatively small grants, averaging about $28,500 each to private, nonprofit agencies that are required to assume the major financial responsibility for the housing projects. In addition, the County has been able to arrange for some county- and State-owned properties to be leased at nominal rates for use as residences for persons with disabilities. Such an approach appears very much in line with the goals of the CDBG program and the emphasis of the Reagan Administration upon local initiatives and the use of grant funds to leverage private sector involvement.

III. NONDISCRIMINATION AND FAIR HOUSING REQUIREMENTS

In addition to programs for developing additional housing opportunities for persons with disabilities, a major Federal responsibility is to assure that currently available housing opportunities are equally open to individuals with disabilities. The primary means for accomplishing such an objective is through laws prohibiting discrimination on the basis of disability in housing.

A. Lack of Coverage Co-Extensive to the Fair Housing Act

Title VIII of the Civil Rights Act of 1968 (42 U.S.C. sections 3601 - 3619) prohibits discrimination in housing on the basis of race, color, religion, sex, and national origin. The coverage of Title VIII is extremely broad, applying to almost all types of housing with the exception of certain private, single family dwellings, and facilities owned or operated by religious groups and private clubs.

Section 504 of the Rehabilitation Act of 1973 (29 U.S.C. section 794) prohibits discrimination on the basis of handicap only in housing programs or activities of the Federal Government or that receive Federal financial assistance. Compared to the coverage of Title VIII, the housing subject to Section 504 is quite limited. Various bills have been proposed that would provide equivalent coverage of handicap discrimination as that provided under Title VIII, generally by simply adding "handicap" to the types of discrimination prohibited in Title VIII. In his July 12, 1983, message to Congress transmitting proposed Fair Housing legislation, President Reagan called for the extension of such legislation to protect people with disabilities, and noted that a Congressional consensus in favor of such an expansion of coverage had emerged in the previous session of Congress (President Reagan, 1983, p. 992). An important element of guaranteeing fair housing opportunities for individuals with disabilities is the need to impose a statutory duty upon landlords, developers, and sellers to make reasonable accommodations for tenants and purchasers with disabilities.

B. HUD Implementation of Section 504 of the Rehabilitation Act of 1973

1. Development of Section 504 Regulations. Currently, Section 504 of the Rehabilitation Act of 1973, as amended, (29 U.S.C. section 794) is the only major piece of Federal legislation prohibiting discrimination on the basis of handicap in the housing area. The Department of Housing and Urban Development does not presently have in place regulations to implement the requirements of Section 504. On April 19, 1978, HUD had originally published a Notice of Proposed Rulemaking for public comment on proposed Section 504 regulations. Upon analyzing the comments received, the Department found that both the organizations representing persons with disabilities and the housing industry were critical of the 1978 proposed rule. On May 6, 1983, HUD published regulations in interim final form (republished with corrections on May 18, 1983), to become effective on June 15, 1983. After complaints about the lack of an appropriate public comment period, the Department announced on

June 15, 1983, that the rule was to be considered a proposed rule, with public comments to be accepted until September 6, 1983.

HUD received a total of 1258 comments upon the 1983 proposed rule. According to the Department's analysis of the comments, only 11 of the commenters -- all from the housing industry -- were favorable to the proposed rule. In November of 1984, HUD distributed to disability rights groups and sent to the Department of Justice a revised draft of proposed regulations. Department of Justice officials reportedly asked for some revisions of the rules to correct provisions believed to be particularly unacceptable to persons with disabilities. To date, no final regulations have been issued.

2. Problems With Proposed Regulations. Much of the dissatisfaction with HUD's proposed Section 504 regulations has centered around certain particularly controversial provisions:

a. The "Peaceful Enjoyment" Criteria

Section 8.3, the definitions section of the proposed regulations, contains a definition of the phrase "qualified handicapped persons." One portion of that definition sets out "essential eligibility requirements" that a handicapped applicant must meet to be eligible for HUD-funded housing. One of the stated requirements is that a handicapped person must comply "with all obligations of occupancy, including the obligation to conduct himself or herself in a manner which will not disturb his or her neighbors' peaceful enjoyment of their accommodation and will be conducive to maintaining the housing facility in a decent, safe and sanitary condition." According to HUD's summary of public comments:

> The basic criticism of this language is that it imposes a double standard because non-handicapped persons are not required to prove that their behavior will not disturb neighbors. Most commenters believe that the inclusion of this language will foster discrimination.

HUD determined that it had received 951 comments on the definition of "qualified handicapped persons;" all but 7 of these comments were critical of the definition. One local housing management company, however, believed that the definition should go even further and require that every handicapped applicant submit a doctor's certificate that he or she can function independently and is not dangerous to society.

HUD's November 2, 1985, revised draft of portions of the proposed regulations attempts to ameliorate some of the criticized impact of the eligibility criteria definition by requiring that admission procedures for handicapped applicants may not differ from the admissions procedures applied to nonhandicapped persons "in such a manner as to screen out, or tend to screen out, handicapped persons, or any class of handicapped persons ..." The draft goes on to permit managers to make "such inquiries as may be relevant" (expressly including inquiries of "such sources as professional staff at hospitals, institutions and related supportive social agencies") to determine whether the handicapped applicant would be "likely to interfere with other tenants in such manner as to diminish their enjoyment of the premises by adversely affecting their health, safety or welfare, or to affect adversely the physical environment or the financial stability of the assisted housing." To the extent that this formulation continues to apply to applicants with disabilities additional criteria not applied to nondisabled applicants and incorporates a presumption that persons with disabilities are more likely to be disruptive, irresponsible, or dangerous tenants, it appears to be susceptible to the same criticisms as the 1983 version.

b. Coverage of Intentional Discrimination Only

In listing the types of discrimination prohibited, the HUD proposed regulations omitted language in the Department of Justice Implementation Guideline regarding the use of criteria or methods of administration that "have the effect of subjecting qualified handicapped persons to discrimination on the basis of handicap." The absence of coverage of unintentional discrimination in housing has been strongly criticized. HUD reported that the 942 commenters addressing the issue were critical of the omission. The failure to prohibit "effects" discrimination is also contrary to the subsequent decision of the United States Supreme Court in the case of Alexander v. Choate (105 S.Ct. 712 (1985)), which held that Section 504 condemns unintentional as well as intentional discrimination.

c. Percentage of New Construction Required To Be Accessible

Section 8.22 of the proposed regulations sets out accessibility requirements for newly constructed HUD-assisted housing. It requires that 5 percent of the units in a project be made accessible for persons with mobility impairments, and that 2 percent be made accessible for people with vision or hearing impairments. Housing developers may request a waiver of these requirements by showing that the percentages exceed the need for such housing in a particular locale. HUD may impose higher percentage requirements upon the request of a State or local government and a demonstration of need, but in no case may the requisite percentage exceed 15 percent.

According to HUD analysis of the comments received, most commenters believed that the percentage figures set for accessible housing were inadequate. Commenters disagreed with the 5 percent requirement for mobility impairment accessibility, the 2 percent figure for visual and hearing impairments, and the overall 15 percent cap. Numerous commenters, including the American Association of Retired Persons and the National Gray Panthers along with disability organizations, argued that 100 percent of newly constructed housing units should be accessible or adaptable. HUD's summary of the comments of the National Gray Panthers, for example, included the view that the percentages for accessibility in the proposed regulations disregard data showing that impairments increase with advancing age and that non-disabled people may become disabled during the course of their tenancies. "If units were required to be adaptable to meet the needs of a variety of disabilities, the distinction between the housing needs of eligible handicapped and eligible non-handicapped persons would fade." A group of 161 comments in favor of 100 percent accessibility or adaptability in newly constructed units argued that doing so would add only 1 percent to the total cost of the units.

d. Accessibility Requirements For Alterations

Section 8.23 of the proposed regulations provides that a facility to be altered must be made accessible if it contains 25 or more units and if the cost of the alterations is 75 percent or more of the replacement cost of the completed facility. According to the HUD summary of public comments, "Most of the comments on this section state that the 75 percent or more of replacement cost threshold for triggering the accessibility requirements ... is too high." Many of the commenters pointed out that a 50 percent figure is commonly used by other agencies and in State laws. Commenters also asserted that fair market value of the facility rather than replacement cost of the completed project should be the pertinent amount considered, since replacement cost is almost always much higher than the market value of a building.

e. Public Housing Accessibility

Section 8.24 of the proposed regulations sets accessibility standards for public housing. HUD reported that most commenters do not feel the section goes far enough in providing accessibility in public housing. Section 8.24(c) states that public housing projects shall not be required to make more than five percent of the units in any modernization project accessible. Many of the commenters criticized the five percent ceiling, particularly in light of the 15 percent cap proposed for other HUD housing. One group of commenters pointed out the irony of having a lower accessibility ceiling for public housing when data indicate that disabled tenants living in HUD projects are disproportionately indigent: "it is incongruous to require fewer accessible units in a public housing project than in HUD housing for tenants who are able to pay some portion of the rent."

3. Complaints of Handicap Discrimination Filed With HUD. Although HUD does not have in effect any final regulations for the implementation of Section 504, the Department has received many complaints of housing discrimination in violation of Section 504. In fact, HUD has been receiving more complaints under Section 504 than all other types of discrimination complaints combined. For 1984, 206 complaints of discrimination under Section 504 were filed with the Department.

In the absence of regulations, HUD has made efforts to process and be responsive to complaints of handicap discrimination. To assist HUD personnel in understanding and dealing with housing issues affecting people with disabilities, the Office of HUD Program Compliance, Fair Housing and Equal Opportunity has distributed a Disability Issues Trainer's Manual. This manual provides instruction and guidance on dealing with issues of discrimination in housing.

Unfortunately, HUD efforts on disability issues are hampered by the absence of any adequate administrative focus for such efforts. There are no appropriately organized, placed, and staffed units charged with dealing with such issues on an ongoing basis, and providing sufficient administrative leverage, coordination, and follow through. Units specializing in disability would be advantageous both within HUD's Fair Housing and Equal Opportunity Division (to guide the enforcement of Section 504 and other legal and regulatory requirements) and within the Office of Policy Development Research (to provide input to HUD disability policy direction).

C. Zoning Restrictions

A major area of discrimination against persons with disabilities that has not yet been addressed in Federal laws concerns local zoning ordinances that have sometimes been used to prevent group homes and other housing alternatives from locating in residential neighborhoods. Unwarranted fears and inaccurate stereotypes have sometimes led neighbors and zoning authorities to oppose group living arrangements for persons with disabilities in particular residential areas. Local zoning ordinances have been used as barriers to prevent the establishment of various housing programs for people with disabilities. Such situations have resulted in numerous court cases and appeals, culminating in a number of judicial decisions generally in favor of the housing units for persons with disabilities. Recently, one such case, *City of Cleburne, Texas v. Cleburne Living Center* (105 S.Ct. 3249 (1985)), was appealed all the way to the United States Supreme Court. The Court ruled that opposition to the group home for mentally retarded people at issue in the case was based on "an irrational prejudice against the mentally retarded" (105 S.Ct. at p. 3260), and declared that "mere negative attitudes, or fear, unsubstantiated by factors which are properly cognizable in a zoning proceeding, are not permissible bases for treating a home for the mentally retarded differently from apartment houses, multiple dwellings, and the like" (Id. at p. 3259). Several states have passed laws prohibiting local zoning restrictions from being interposed to block alternative living programs for individuals with disabilities.

To prevent the need for a case-by-case court battle whenever neighbors object to a residential program for persons with disabilities, a Federal prohibition of discriminatory zoning ordinances is needed. A partial model for such a provision is provided by Section 815 of Title VIII of the Civil Rights Act (42 U.S.C. Section 3615). That Section declares State or local laws requiring or permitting housing discrimination invalid to the extent that they are inconsistent with the requirements of Title VIII; the laws are not themselves struck down, but their application is invalidated whenever it constitutes discrimination prohibited by Title VIII.

A similarly worded statute could prohibit, as unlawful discrimination, any application of local zoning ordinances to prevent the establishment or operation of alternative living arrangements for persons with disabilities in residential zones. Such a law would provide a Federal overriding of local zoning laws to the extent that they require or permit the discriminatory use of zoning restrictions to eliminate appropriate housing options for citizens with disabilities.

IV. COSTS AND BENEFITS

As the previous sections have indicated, two major efforts of the Federal Government to promote the availability of appropriate housing opportunities for people with disabilities are equal housing opportunity laws and housing construction and rent subsidy programs. Such initiatives may be justified on the basis of purely humanitarian concerns that disabled persons be afforded minimally adequate shelter and an equitable chance to pursue housing opportunities. In addition to such considerations of equity and basic human rights, the Council has also examined the costs and potential benefits of such efforts to secure opportunities for appropriate housing for people with disabilities. Although available data are not precise, current reliable estimates strongly suggest that efforts to promote appropriate housing for individuals with disabilities make economic as well as humanitarian sense.

Equal housing opportunity laws impose a duty upon landlords and developers covered by these laws not to discriminate against persons with disabilities. To the extent that this simply requires the cessation of discriminatory admission standards, rules, practices, or attitudes, it does not cost anyone any money, and would clearly be economically beneficial insofar as it enhances the independence and self-sufficiency of persons with disabilities.

In the Council's view, equal housing opportunity laws should also require the architectural accessibility of all housing constructed in the future that is subject to these laws. This latter requirement will involve some costs, but, according to studies, relatively small ones. A 1979 report published by the U.S. Department of Housing and Urban Development, The Estimated Cost of Accessible Buildings, provides the most authoritative study of accessibility costs. It contains cost estimates for achieving accessibility in various types of buildings, including high rise towers, garden apartments, and single family dwellings. Figures are provided on the costs of making structures either adaptable or adapted for housing persons with disabilities. Adaptable housing, for purposes of the study, means that it satisfies housing adaptability standards of the American National Standards Institute (ANSI), which require that a dwelling unit be basically accessible and easy to convert to full accessibility through such means as removing two base cabinets under counters in the kitchen and installing grab bars in the bathroom for people who need these features (particularly wheelchair users). Costs of adapted housing includes the additional cost for adapting a residential unit by removing the cabinet fronts, installing grab bars, etc. (HUD, 1979, #2, p.5). The study found the costs of incorporating accessibility in the design and construction of residential structures to be as follows:

Type of Building	Adaptable	Adapted
High Rise Tower	0.98 percent	1.6 percent
Garden Apartments (to make all ground floor units accessible)	0.59 percent	.93 percent
Single Family House	2 percent	3 percent

(HUD, 1979, #2, pp. 34, 57, 66)

The relatively small costs of accessibility in new construction have been confirmed in other studies. In a 1982 publication, the Architectural and Transportation Barriers Compliance discussed several such studies, and quoted findings of one-half of one percent and one-tenth of one percent as the cost of accessibility features in new buildings (About Barriers, p. 5). A 1975 Report to Congress prepared by the General Accounting Office concluded that "the additional cost for accessibility features included in the original construction program may only be one-tenth of 1 percent of total construction cost" (GAO, 1975).

Given the small proportion of these costs compared to overall project costs, it is not an egregious burden to expect that accessibility should be built into all construction funded by HUD or subject to Fair Housing Laws. And from a governmental and societal perspective, such costs are offset by benefits that accrue from reducing dependency costs and increasing opportunities for productivity and independence for individuals with disabilities. Another HUD study published in 1979, A Cost-Benefit Analysis of Accessibility, presented a cost-benefit analysis of the removal of architectural barriers from residential and nonresidential buildings. The study found that "The net benefits attributable to the removal of architectural barriers are, in most cases, very large" (HUD. 1979, #1, p. 67).

Likewise, it appears that Federal programs providing subsidies for the construction (i.e., Section 202) or rental (i.e., Section 8 and the Voucher program) of housing for persons with disabilities are economically beneficial to the nation, when one considers that the alternative to securing adequate housing options for persons with disabilities is the costly institutionalization of such persons and the continuation of federally underwritten dependency costs. The Digest of Data on Persons with Disabilities, published by the Congressional Research Service in 1984, estimates that 1.3 million Americans reside in nursing homes, 232,340 in inpatient mental health facilities, and 152,000 in public residential facilities for mentally retarded persons (CRS, 1984, pp. 10, 14, 16). The results of a Survey of Institutionalized Persons conducted by the Bureau of the Census in 1976 found that 1,550,120 persons were in long term residential care facilities, including: facilities for mentally retarded persons (189,210); facilities for physically handicapped persons (37,780); children's facilities (43,790); psychiatric institutions (65,400); nursing homes (1,182,670); and other facilities (31,270) (U.S. Bureau of the Census, 1976, p. 108).

There are no precise statistics indicating what proportion of this institutionalized population could reside in the community if appropriate housing were available. Information obtained at consumer forums conducted by the Council suggests that the number of such situations is sizeable. Anecdotal examples include:

o The young man with a spinal cord injury and resulting quadriplegia who continues to reside in a hospital many months after his medical release would have been warranted solely because he cannot find any accessible housing in his local community.

- The mentally retarded young woman who is kept in a State institution year after year, even though she has been evaluated as capable of living in the community, because no community group home residence is available.
- The former mental patient whose attempts to reestablish an independent life are frustrated by the refusal of landlords in her local community to rent her an apartment.
- The deaf man whose ability to earn a living and live independently depend upon his taking a promising job offer, but who cannot find any affordable housing within a reasonable proximity of the job (and several owners of suitable units have refused to rent to him).
- The low-income couple, each with cerebral palsy, who have been unable to secure housing in public housing projects and are forced to stay in a federally funded State institution.

For those individuals who could live in the community if they are able to obtain appropriate housing, the potential savings of Federal dollars are dramatic. Depending upon geographical location, it costs between $30,000 and $110,000 per year for each individual who is elderly and/or disabled to be housed in federally-funded facilities. This should be compared with the average expenditure of $7,121 per year for a Section 8 certificate in a Section 202 project. And the current $50,000 per unit allocation for Section 202 construction is comparatively quite small considering that it may provide a housing unit suitable for persons with disabilities for thirty or forty years or more. When compared with the alternatives of long-term institutionalization and Federal dependency entitlements, the expenditures necessary to secure appropriate housing opportunities for persons with disabilities can be seen to be money well spent. And this is without even considering the difficult-to-estimate returns that result whenever an individual with a disability is permitted to live in the community and becomes an economic contributor by earning money, paying taxes, and purchasing goods and services.

RECOMMENDATIONS

1. Congress should prohibit housing discrimination against persons with disabilities on as broad a basis as race, color, religion, sex, and national origin discrimination are prohibited under Title VIII of the Civil Rights Act of 1968.

Recognizing that one of the nation's largest minorities -- that of persons with disabilities -- is omitted from the coverage of the Fair Housing Act, the Council recommends expanding coverage of housing nondiscrimination requirements to protect persons with disabilities. This may be accomplished either by amending Title VIII of the Civil Rights Act of 1968 to include "handicap" or by enacting a separate law (for further discussion, see the Council's recommendations on "Equal Opportunity Laws"). President Reagan has called for expansion of Fair Housing legislation to protect people with disabilities, and has noted an apparent Congressional consensus in favor of such an expansion of coverage (President Reagan, Message to the Congress Transmitting Proposed Fair Housing Legislation, July 12, 1983, p. 992).

Such a prohibition should make clear that developers, landlords, and real estate management companies may be required to make reasonable accommodations for individuals with disabilities. It should also encompass a requirement of compliance with full accessibility standards as described in Recommendation 2 below. The statutory prohibition of discrimination in housing should declare local zoning ordinances invalid to the extent that they prevent the establishment or operation of community residential alternatives for people with disabilities in all housing covered by Title VIII.

2. Congress should require that all housing units constructed or substantially altered with Federal financial assistance, Federal loans, Federally subsidized or insured loans, or by agencies of the Federal Government, should be required to meet accessibility standards.

In light of data indicating that such modifications entail a very small percentage of costs of new housing, Federal agencies should implement a plan and develop regulations requiring that all housing units be adaptable, based upon Uniform Federal Accessibility Standards now in effect under the Architectural Barriers Act of 1968. These standards provide technical specifications for a universally accessible floor plan, e.g., level or ramped entrances, wide doors, lower outlets and heating controls, accessible bathrooms with reinforced walls, accessible kitchens, and lower door knobs and locks. Pursuant to analysis of the costs of the modifications, and pursuant to minimum guidelines that should be established by the Architectural and Transportation Barriers Compliance Board, requirements for adaptability in housing may also impose additional requirements for modifiable accessibility, such as adjustable shelves in closets, and warning devices and flashing lights for people with hearing impairments. This type of universally accessible housing unit would be easily modified to meet the individual needs of a person with a disability. Specific standards for applying such accessibility requirements should be developed with input from the National Council on the Handicapped, representatives of the housing construction industry, such as the National Association of Home Builders, and organizations of persons with disabilities. HUD should chair a Federal interagency committee to assist and coordinate the development of accessible housing units under the jurisdiction of other Federal agencies, consistent with minimum guidelines established by the Architectural and Transportation Barriers Compliance Board.

Accessible housing is not only an urgent present need for citizens who currently have disabilities, but, as the U.S. population becomes increasingly older with the maturing of the baby boom generation, accessible housing will become increasingly more important for the growing population of elderly citizens. Statistics are clear: many Americans who do not now have disabilities will incur disablities in their later years and will find themselves searching for accessible housing. Imposition of an adaptability requirement on housing construction today is one important step toward addressing the growing need for such housing in the future.

3. Congress should direct the Department of Housing and Urban Development that programs to provide rent subsidies for persons with disabilities through both Section 8 certificates and the housing voucher program should be made permanent and given a high priority.

The Administration-endorsed voucher program, initiated as a demonstration project, has proven to be an effective vehicle for providing persons with disabilities the opportunity to select their own places of residence. In addition, the traditional Section 8 certificate program continues to serve an important purpose in assisting disabled people by providing rent subsidies. The Section 8 New Construction program is a major financial incentive for developers to construct Section 202 housing for disabled persons. Twenty percent of all Section 8 certificates should be set aside for persons with disabilities. HUD should clarify maximum rent criteria under Section 8 to uniformly permit persons with disabilities to share apartments with others. Income eligibility criteria for Section 8 certificates and vouchers should be based upon actual net income of applicants with disabilities after the deduction of disability-related expenses.

4. Congress should direct the Department of Housing and Urban Development to reorganize the Section 202 program to provide a range of housing options for persons with disabilities, and to include a program of demonstration grants to agencies such as Independent Living Centers to develop model housing options, including transitional living programs, group residences, and other alternatives.

The Administration has recognized that private production may not be sufficient to meet the housing needs of elderly people and persons with disabilities (HUD, 1984, p. 61). Consequently, Section 202 or a similar federally funded program is needed to stimulate the construction of additional housing units for people with disabilities. The traditional Section 202 program, however, has engendered certain problems, such as isolation of people with disabilities, and lack of age-appropriate social integration. As HUD is reconsidering the structure and goals of the Section 202 program during the current moratorium on Section 202 construction, the program should be reorganized to provide several different types of housing options for people with disabilities. These would include group homes and other disability-specific residential programs for persons needing supervised supportive living environments, as well as integrated housing in the community for the majority of persons with disabilities who do not need such supervised support.

All housing constructed under such a program should meet general standards of accessibility, as discussed in Recommendation 2 above. The developer/management of such a project should be required to provide tenants with disabilities the option of being interspersed with nondisabled tenants. Tenants with disabilities should also be integrated with other tenants on an age-appropriate basis.

A HUD program should be established to initiate demonstration projects to provide funds to agencies such as Independent Living Centers to develop model housing options for future HUD construction funding. Such housing alternatives, including transitional living programs, group residences, and other arrangements, will provide alternative models to the traditional Section 202 high-rise apartment buildings, and stimulate more appropriate housing opportunities for citizens with disabilities and elderly persons.

These recommendations do not necessarily contemplate any increase in funding of the Section 202 program, but rather a reallocation of the uses made of Section 202 funds at current spending levels.

5. Offices responsible for disability issues should be established within HUD's Fair Housing and Equal Opportunity Division and within the Office of Policy Development and Research.

These two offices would provide much needed administrative focus on disability-related issues within the Department. The former would serve to guide the enforcement of Section 504 and other legal and regulatory requirements, while the latter would provide important input to HUD disability policy direction.

6. Congress should direct HUD to issue appropriate regulations for the implementation of Section 504 of the Rehabilitation Act of 1973.

A timeline should be imposed for the issuance of Section 504 housing regulations. HUD should be directed to involve disabled individuals, the National Council on the Handicapped, and disability organizations in the process of developing and issuing such regulations. Such regulations should not permit the imposition upon housing applicants with disabilities of any standards or criteria, such as neighbor attitudes or apartment maintenance, unless such criteria are necessary, nondiscriminatory, and are imposed upon all tenants. HUD's regulations should provide that recipients of HUD funds are prohibited from unintentional as well as intentional discrimination on the basis of handicap. Recipients should be required to assure that practices, procedures, and facilities do not inadvertently exclude or disadvantage tenants or potential tenants with disabilities. The regulations should also require compliance with accessibility requirements as set out above in Recommendation 2 above.

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7. Additional programs should be initiated to leverage existing private sector funding and to provide incentives and financial resources for the development of housing opportunities for people with disabilities.

Federal Housing Administration (FHA) and other governmental and private housing loan funds should be equally available to persons with disabilities. Federal housing loan programs whose eligibility criteria include income level ceilings should reflect actual net income after the deduction of disability-related expenses.

Rather than focusing on making and administering housing loans, HUD should be authorized to "buy down" interest rates on loans offered and administered by private financial institutions. Other incentive programs should include:

a. Expanding the existing Federal income tax deduction for the removal of architectural barriers, including increasing the amount eligible for deduction;

b. Instituting low-interest loans or loan guarantee programs to provide people with disabilities who are eligible for rent subsidies the option of purchasing a comparable home, thus reducing the long-term need for rent subsidies; and

c. Establishing low-interest loan programs or tax incentives to encourage private sector construction of single-family housing, cooperatives, and condominiums for individuals with disabilities.

These proposals reflect the fact that the average annual per unit expenditure for rent subsidies in 1985 amounted to $6,459 in

Section 202 facilities; $4,659 under Section 8 existing certificates; and $3,404 under the voucher system. Such amounts of money could be used to provide interest subsidies that would enable eligible individuals with disabilities to purchase homes at low interest rates, and to eventually cease needing any housing subsidy.

8. HUD and the private sector should be encouraged to develop training grants, supplemental teaching positions, awards, and other innovative programs for promoting architectural planning that incorporates the concept of universal accessibility.

Aspiring architects and planners should be provided the training necessary to enable them to develop innovative designs implementing universal accessibility in new and rehabilitative construction. Such innovations may dramatically transform the design and construction of housing, public and private buildings, schools, work places, and public transit systems, and eliminate environmental barriers to elderly persons and people with disabilities.

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TOPIC PAPER G:

COMMUNITY-BASED SERVICES FOR INDEPENDENT LIVING

National Council on the Handicapped

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ACKNOWLEDGMENT

This is one of a series of ten topic papers developed by the National Council on the Handicapped as part of its Special Report to the President and Congress: TOWARD INDEPENDENCE: An Assessment of Federal Laws and Programs Affecting Persons with Disabilities--With Legislative Recommendations. The members of the National Council on the Handicapped wish to expressly acknowledge with appreciation the special contribution made to this paper by Margaret A. Nosek.

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I. INTRODUCTION

Community-based services that promote independence for Americans with disabilities is a promising service delivery strategy for our nation. Environmental inaccessibility, overprotective and restrictive attitudes on the part of relatives and providers, lack of economic resources, ignorance of the concepts and techniques of independent living, lack of community based support services, and a bias toward institutions in current service-providing systems, however, restrict the ability of many persons with disabilities to achieve and maintain maximum independence. Billions of public dollars are currently spent on maintaining millions of disabled Americans in situations of unproductive dependency, which impose artificial limits on disabled individuals' potential to become contributing members of society. Significant savings will be realized as America moves toward becoming an accessible society, and as more severely disabled people become independent, contributing citizens.

The Council believes that the majority of persons with disabilities are able to sustain themselves and contribute to society provided that accessible facilities and services are available and they are assisted with overcoming the attitudes and barriers that unnecessarily restrict and prohibit them from attaining their goals for self-sufficiency and independence. Under ideal circumstances, many persons with disabilities can and do meet their own needs through their own self-sufficiency, and by relying, when needed, on relatives, friends, and private and public sources of assistance. When appropriate services and assistance are available, few individuals with severe disabilities should be placed in institutions.

Independent living is defined in the National Policy for Persons with Disabilities (1983) as control over one's life based on the choice of acceptable options that minimize reliance on others in making decisions and in performing everyday activities. This includes managing one's affairs, participating in the day-to-day life of the community in a manner of one's own choosing, fulfilling a range of social roles that includes productive work, and making decisions that lead to self-determination and minimize nonproductive physical and psychological dependence upon others. The independence defined here implies an optimally responsible and productive exercise of the power of choice. It implies that each disabled person, regardless of his or her mental or physical ability, should be encouraged and assisted to achieve maximum levels of quality of life, independence and productivity in the least restrictive environment and with due respect for cultural or subcultural affiliation.

Services to support independent living must be tailored to the needs of the individual. Persons with severe physical disabilities usually require assistance with personal care, domestic tasks, transportation, equipment maintenance, and modifications of home and work place for architectural accessibility. Those with sensory disabilities require reader and interpreter assistance with communication and expression. Persons with mental impairments who wish to live independently may require some assistance with cognitive tasks as provided by advocates. All can benefit from information and referral about services and service providers, training in independent living skills, assistance in gaining mobility in the community, and individual advocacy. All who have extraordinary medical and personal care expenses require private and/or public resources to help cover such expenses. Those who are not employed usually require income maintenance support and financial assistance with daily living expenses.

Services for independent living include any formal or informal assistance that is needed by people with disabilities who are trying to increase control of their life, productivity, and participation in the community. Generally, these services are delivered by community-based organizations that are privately or publicly funded. However, services rendered by residential institutions can also be considered independent living services if they assist residents to achieve maximum independence in the least restrictive environment. In this sense, traditional long-term care service providers provide independent living services if they assist residents to reach their independent living goals.

Who can use community-based independent living support services? Almost all persons residing in private and government-operated institutions, regardless of the severity of their disability, could benefit in some way from independent living support services. For a large percentage, it could mean being able to live in the community in a residence and lifestyle of their own choice and with the opportunity to realize their potential for productive contributions to society. For those with the most severe disabilities, it could mean receiving life support and enrichment services in a dignified and humane manner that maximizes their quality of life. Services for independent living could benefit those rejected by or who have failed in the vocational rehabilitation system. Potential beneficiaries also include the uncounted millions of disabled persons who live in rural areas and have little access to service providers of any kind, or who reside with families or in small group settings that restrict their ability to control their lives and reach their productive potential.

How many people could use independent living support services? In 1981, approximately 2,138,970 disabled persons were served in 38,975 residential facilities at a cost to the Federal and State government of $22.8 billion. These are totals of the following figures:

- o 499,169 persons with mental illness who were served in 277 State hospitals for $4.5 billion (Goldman, Gattozzi, & Taube, 1981),
- o 243,669 persons with mental retardation who were served in 15,633 residential facilities for $5.9 billion (Smith, 1984),
- o 1,396,132 elderly and physically disabled persons who resided in 23,065 nursing homes (Sirrocco, 1983) and other long-term care facilities at a cost to Medicaid of $12.4 billion (National Study Group on State Medicaid Strategies, 1983).

In 1984, State vocational rehabilitation agencies closed

131,572 cases which had not reached their rehabilitation goals. Out of almost 600,000 applicants, 245,435 were rejected as ineligible. Another 48,372 applicants were placed in the category of extended evaluation; that is, they were not rejected, but were not yet found to be eligible or ineligible for vocational rehabilitation services (Department of Education, 1985). Although there may be some overlap between these figures and the number of people in residential facilities, the total number of persons who sought disability-related services and who could extensively use independent living support services is probably more than 2.5 million.

II. LEGISLATION

Following is a description of legislation which has given rise to and supported community-based services for independent living.

A. Independent Living Legislation

Dalrymple and Richards (1983) gave a thorough analysis of the development and state of implementation of the key piece of legislation underlying the expansion of the independent living movement. Since 1920, a Federal/State rehabilitation program has existed to provide services to disabled people who could demonstrate immediately achievable vocational goals (PL 66-236). The program was amended in the 1960's to authorize a vocational evaluation period of up to 18 months. As a result of this extended evaluation clause, many previously excluded disabled people were able to obtain services from vocational rehabilitation which enhanced their abilities to live independently; however, if they were not vocationally ready at the end of the evaluation period, they were dropped from the rehabilitation program.

In the next few years, proponents of the independent living movement--including disabled individuals and their family members, rehabilitation professionals, health professionals, policy makers, and other advocates--lobbied for changes in the Federal/ State rehabilitation program. In particular, they urged changes in two respects: one, elimination of the requirement of vocational potential, and two, greater involvement of disabled people in developing policy for the program (Lorenz, 1982).

In the 1970's, legislation authorizing provisions of independent living services without requiring a vocational goal was passed by Congress but received a presidential veto. A substantial achievement was made in 1973, however, when funds for a Comprehensive Needs Study were authorized by Congress to establish five research and demonstration projects to provide independent living services. Finally, in 1978, independent living legislation was passed which did not require vocational potential as a requirement for participation. However, this took form as a separate title of the Act and not as an amendment changing the focus of the existing vocational rehabilitation program for which the independent living supporters had hoped.

This independent living entitlement, which is Title VII of the Rehabilitation Act, contains three sections of current interest. Following is a summary of these sections and an assessment of the extent to which each section has been fulfilled to date.

1. Part A. Comprehensive Services. The purpose of this title is to authorize grants to assist States in providing comprehensive services for independent living designed to meet the current and future needs of individuals whose disabilities are so severe that they do not presently have the potential for employment but may benefit from vocational rehabilitation services which will enable them to live and function independently (Rehabilitation Act, 1984). States are thus authorized to provide comprehensive independent living services, including traditional services such as vocational counseling, physical rehabilitation, orthotics and posthetics, and non-

traditional services, such as health maintenance, recreational activities, services for children, and housing modification. The scope of service provision appears to be from birth to death. An especially notable requirement of Part A is that disabled consumers have a substantial role in developing the State's plan of service. States are also required to give assurances in their State plans that no less than 20% of the funds received by a State under Part A will be used to make grants to local public agencies and to private nonprofit organizations for the conduct of independent living services (unless a waiver of this requirement is obtained from the Commissioner of the Rehabilitation Services Administration).

Fulfillment: To date, $5 million have been appropriated by Congress to implement Part A. It should be noted that versions of the Part A program (independent living services without vocational requirements) are presently being operated by State agencies for mentally disabled people, visually disabled people, and hearing impaired people.

For people with mental impairments, State mental health and mental retardation agencies nationwide have been given authority and substantial funding to carry out community programs to facilitate independent living for mentally retarded and mentally ill people. Some programs for this disability group have been developed by combining Housing and Urban Development loan/subsidy housing programs with operating funds from combined State funds and Federal income support sources such as Social Security Disability Insurance and Supplemental Security Income. In addition, community mental health centers provide a wide range of services for mentally disabled persons, including counseling, day programs, and, frequently, housing and supportive services. One missing element, however, though, appears to be an extensive goal-oriented case management coordination system like the one found within vocational rehabilitation agencies.

Many State agencies for blind individuals have independent living programs that include independent living coordinators along with mobility and homemaker specialists. More States are beginning to establish councils for people with hearing impairments. While these programs do not limit service advocacy and provision to those people with vocational goals, they are frequently small programs with limited staffing and few direct services.

Physically disabled people without apparent vocational potential, however, are still ineligible to receive federally-funded services from State vocational rehabilitation agencies. Recently, a few State legislatures have authorized the use of State funds to provide certain independent living services, including attendant care, peer counseling, independent living skills training, and others. Among these States are Texas, California, New York, Massachusetts, Maine, North Carolina, Ohio, Minnesota, and Wisconsin.

2. Part B. Centers for Independent Living. This part authorizes grants to establish independent living programs and requires substantial involvement of disabled people in policy direction, management, and employment within the independent living program. The general intent of Part B is provision of

services that are multiple and comprehensive, such as intake counseling, advocacy, independent living skills training, housing and transportation, referral and assistance, health maintenance, peer counseling, education and training, recreation, attendant care, and others.

Fulfillment: In Fiscal Year 1979, $2 million was appropriated for Part B, funding only ten grants. Subsequent appropriations were $15 million for Fiscal Year 1980, $18 million for Fiscal Year 1981, and $17.28 million for the Fiscal Year ending September 1983, expanded to $19.4 million by continuing resolution and maintained at that level for 1984. Appropriations for 1985 are $22 million. Altogether, more than 159 programs are being at least partially supported by these funds.

For the most part, grant awards were made to State vocational rehabilitation agencies that subcontracted with community-based organizations which had boards largely composed of disabled persons. There are a small number of variations on this pattern. For instance, a small number of grant awards were made to local organizations when State agencies chose not to apply. Also, in a few instances, State agencies chose to operate independent living programs themselves, fulfilling the requirement of substantial consumer involvement in policy direction by setting up advisory boards of disabled persons.

The most comprehensive analysis to date of the full range of independent living programs has been done by the Independent Living Research Utilization Project. They have identified 281 programs which deliver independent living support services (ILRU Directory, 1985). Their 1983 survey of these programs produced significant data (ILRU Registry, 1984; Veerkamp, 1984). Of the 157 programs responding to the survey, 63% met the criteria for an independent living center, including being consumer-controlled and community-based. The average profile of a program's budget was 79% Federal and State funds, 4% local funds, 8% private agency or foundation funds, and 9% program generated funds (fees, memberships, etc.). Seventy percent of the programs served only persons in the immediate community, 15% served those in rural areas, and 13% served those in other cities around the State. The most prevalant disability types served were spinal cord injury (18%), blindness (16%), mental retardation (12%), and cerebral palsy (10%).

In the six years since Title VII was incorporated into the Rehabilitation Act, independent living centers have developed the experience needed to establish realistic operating standrds and policies. They have also matured to the stage of being able to sustain a national organization. National standards that will assure that quality services standards are provided by all independent living centers receiving Federal funding were approved by the National Council on the Handicapped in 1983. This is an important step in establishing independent living centers as a reliable source of quality services that help persons with severe disabilities to achieve their goals for self-sufficiency. A destabilizing factor is the absence of core funding for these centers. From year to year, each center does not know the amount of funding it will receive from the Federal Government (if any) during the coming year for funding. Given the relatively limited funding available, this frequent reapplication process diverts energy from improving community resources and service delivery. In addition, the absence of a reliable funding source makes it difficult for the centers to firmly establish themselves within the service delivery community and to compete as successfully as they might for other sources of funding. Over the long run, successful centers must obtain funding from a range of public and private sources. For this reason, they should actively involve private business and other community leaders in their planning and fundraising processes.

3. Part C. Independent Living Services for Older Blind Individuals. This part authorizes grants to States to provide independent living services to persons 55 years of age or older whose visual impairment makes employment difficult to attain but for whom independent living goals are possible. However, these individuals should be able to receive services under Part A and from independent living centers funded under Part B.

Fulfillment: No appropriations have been made for Part C. For the Fiscal Year 1986 Budget, the House has recommended a funding level of $5 million.

B. Legislation for Community-based Services for Persons with Mental Retardation.

Conley and Noble (1985) have analyzed legislation relevant to the move toward community-based services for persons with mental retardation. In 1971, the Intermediate Care Facilities for Mentally Retarded Persons (ICF/MR) program was enacted, primarily to improve the quality of care being provided in State institutions. Almost from the beginning, however, the program was used to support some community residential programs. In 1976, the Social Security Act was amended to permit Supplemental Security Income (SSI) payments to be made to public residential facilities with 16 or fewer residents. Previously, SSI payments could not be made to residents in public facilities. In 1981, Title XIX of the Social Security Act was further amended to allow the Secretary of the Department of Health and Human Services to grant waivers to States to use Medicaid funds to pay for non-medical services to elderly and disabled persons who would otherwise require institutional care. The Home and Community-Based Waivers Program was explicitly designed to promote the development and provision of community-based care.

C. Legislation for Community-based Services for Persons with Mental Illness

Federal funding of services for persons with mental illness is authorized largely by the same legislation as services for mentally retarded persons, that is, Titles XVIII, XIX, and XX of the Social Security Act. Prior to 1981, federally-funded community mental health centers (CMHCs) were funded in part through National Institute of Mental Health (NIMH)-initiated categorical grants to the individual CMHCs. With the initiation of the Alcohol, Drug Abuse, and Mental Health Services Block Grant to the States, NIMH no longer monitored formerly federally-funded CMHCs. Instead, NIMH reclassified these organizations into other organization types according to the types of services they directly controlled and administered. As a result of this reclassification, most organizations formerly classified as federally-funded CMHCs were reclassified as freestanding psychiatric outpatient clinics, non-Federal general hospital psychiatric services, and multiservice mental health organizations. The term "community mental health center" is no longer used (Manderschied, Witkin, & Bethel, 1985).

D. Social Security Legislation Affecting All Persons with Disabilities

A major portion of the resources which support persons with severe disabilities of all ages in institutional settings comes from the Social Security Act. While other provisions of this Act enable people to receive a variety of social services and income support benefits, strict eligibility requirements regarding income and the involvement of medical professionals in the delivery of services hinder the ability of beneficiaries with disabilities to live independently in community settings.

Many problems and inadequacies exist within the Social Security system for persons with disabilities. Attendant services are not readily available to those who need it. Funds for this service are generally very limited and eligibility is very strict. There is a general lack of comprehensive case management assistance for independent living, including transition services from the hospital to the home, institution to community, and from parents' home to independence in the community and little assistance in equipment selection and maintenance and in locating sources for other independent living support services. The legislation does not authorize enough funding for education and training for independent living or for assistive devices. Habilitative and rehabilitative training, including prevocational services, are often not available under

Medicaid or Medicare funding. There is no comprehensive medical insurance for disabled persons who are unable to obtain adequate insurance through their employer or who are ineligible for other Federal medical benefits.

Specifically, the following provisions in the Social Security Act relate to independent living for persons with disabilities:

1. Title II: Old Age and Surviving Dependents Insurance. Medicare eligibility currently terminates for disabled beneficiaries who engage in substantial gainful activity, despite continuing disabilities.

2. Title V: Maternal and Child Health/Crippled Children Services. Discretionary funds under this title could be available to demonstrate the value of attendant services for adolescents to achieve peer integration and independence, and to encourage States to provide attendant services and other in-home support services in order to reduce hospitalization.

3. Title XVI: Supplemental Security Income. SSI benefits for disabled beneficiaries who require some attendant services are the same as for those who do not require attendant services, even though the former can have considerably higher living expenses. Veterans Administration legislation has provisions for extra funding for "essential persons" who provide valuable personal assistance to the beneficiary with a disability. Such supplementary benefits are also not available from States.

Under current law, an individual with a disability who stops working for disability-related reasons and becomes eligible for Social Security Disability Insurance (SSDI) will have no medical insurance for two years due to the Medicare wait period, unless they are financially capable of converting any prior coverage to an individual plan. Because persons who work generally have assets in excess of $1,500, the cannot qualify for SSI or Medicaid. Conversely, persons who receive SSDI or SSI also receive medical benefits which can rarely be matched by private insurers if they choose to attempt a return to work. Section 1619 (a) and (b) is a demonstration project which attempts to remediate this problem for those who receive SSI by allowing them to continue receiving Medicaid benefits despite engaging in substantial gainful activity.

4. Title XVIII: Medicare. Certain independent living support services are available only to those who are considered "home bound," and these services must be supervised and sometimes provided by skilled nurses. Personal assistance (attendant services) and other in-home support services are available only to persons leaving hospitals or extended care facilities on a very short time-limited basis. For applicants for Medicare benefits, there is a two year wait period.

5. Title XIX: Mediciaid. Attendant services are sometimes available but not mandatory under State Medicaid plans. The income limit for the "medically needy" category is 133% of the AFDC level instead of the SSI level, which is higher. Independent living centers are not currently included as eligible providers under this funding. Medicaid-funded services must be delivered in the beneficiary's "own home," thus limiting

participation in community activiites.

6. _Title XX: Social Services Block Grant._ Independent living services receive very little, if any, funding under this title even though the title's purpose is to enhance life in the community.

III. INDEPENDENT LIVING FOR PERSONS WITH SEVERE DISABILITIES

Prior to the independent living movement, traditional services for persons with severe disabilities emphasized medical recovery and employability as the major indicators of success. This narrow focus relegated a large population of persons with disabilities to the limited life options of institutional placement or extensive dependence on family care. The potential for recovery or employment and the ability of people with disabilities to live independently in the community either were not recognized or were grossly underestimated by the rehabilitation and social service systems. In response to the inherent injustice of this situation, independent living training and support services began to be delivered by traditional providers and new entities called independent living programs.

Conceptually, "independent living program" is generic--the most broadly defined term relating to organizations that work with disabled individuals who wish to live independently. Several different kinds of independent living programs exist. They differ from one another in at least six primary areas: the service setting may range from residential to nonresidential; the service delivery method may range from direct to indirect, or a combination of both; the service delivery style may range from professional to consumer; the vocational emphasis may range from primary to incidental; the goal orientation may range from transitional to ongoing; and the disability type served may range from single to many. The features of the independent living program are determined by the needs of the consumers served, the availability of existing community resources, the physical and social make-up of the community, and the goals of the program itself. Custodial care facilities and primary medical care facilities are specifically excluded from the definition of an independent living program.

The development of independent living centers and the independent living movement began about 15 years ago. The movement was initiated primarily by young adults with physical disabilities who sought to broaden the approaches and services available to them so that they might acquire the knowledge, skills, confidence, and assistance they needed in order to participate more fully in society. The practice of delivering independent living support services to disabled persons by disabled persons combined with advocacy for community accessibility had its start in Berkeley in the early 1970's. The Berkeley Center for Independent Living (Zukas, 1975) and the Boston Center for Independent Living (Fay, 1977) became models for the delivery of these services.

The philosophical foundations of the independent living movement and its impact on individuals and community life as demonstrated by these early programs were documented by Pflueger (1977) and DeJong (1979). DeJong set out three major propositions that underlie the philosophical context of the community-based independent living movement:

- Consumer Sovereignty--disabled persons, the actual consumers of the services, not professionals, are the best judges of their own interests. They should ultimately determine how services should be organized on their behalf.

- Self-Reliance--disabled persons must rely primarily on their own resources and ingenuity to acquire the rights and benefits to which they are entitled.
- Political and Economic Rights--disabled persons are led to participate fully and freely in the political and economic life of the community.

The centers for independent living in Berkeley and Boston established the model upon which independent living legislation is based. This model has been defined by Frieden et al. (1979) as a community-based, nonprofit, nonresidential program which is controlled by the disabled consumers it serves, and provides directly or coordinates indirectly through referral those services which assist severely disabled individuals to increase personal self-determination and to minimize unnecessary dependence upon others. The minimum set of services provided by an independent living center include housing assistance; referral of attendants, readers, and/or interpreters; peer counseling, financial and legal advocacy; and community awareness and barrier removal programs. Other services that are either provided or coordinated by independent living centers include transportation provision or registry, peer counseling, advocacy or political action, independent living skills training, equipment maintenance and repair, and social-recreational services.

In 1978, Congress authorized direct support of independent living programs as part of the discretionary programs of the Rehabilitation Services Administration (RSA). The Rehabilitation Act of 1973 was amended to add Title VII--Comprehensive Services for Independent Living. As expressed in the legislation, Title VII was intended to assist in development of community-based service centers to provide information and referral, transportation, attendent care, peer counseling, skills training, and other services. The goal was to facilitate the integration of severely disabled adults into the mainstream of community social and economic life, i.e., to decrease their dependence and increase their self-determination and ability to be productive, contributing members of society.

Title VII authorization drew upon the program development experience of early independent living centers and led to the substantial growth of independent living centers across the country. Using an approach that philosophically and operationally differs from those of more traditional service systems, the independent living centers actively developed and implemented needed programs to facilitate increased independence for the people they sought to serve.

In short, the impetus and strength of the independent living movement resulted in a viable service alternative that: 1. emphasized consumer sovereignty, self-reliance, and economic and political rights; 2. resisted approaches that put the onus of the problem on the consumer and left decisions about service in the hands of the professional; and 3. resisted the use of assessment systems that were experienced as paternalistic. The hallmark of the independent living movement is advocacy for change on both the individual and community level.

As a policy issue, independent living has only recently been examined (Galvin, 1980; Siegman, 1980; Dalrymple & Richards, 1984). In 1983, the concepts of independent living were incorporated into the National Policy for Persons with

Disabilities by the National Council on the Handicapped. This was the first policy document to actively apply the concepts of independent living to all disability groups and call for an independent living orientation in the provision of all human services.

Very little has been written about independent living for populations underrepresented in programs funded under Title VII. Katz (1965), Braddock (1978) and Sigelman and Parham (1981) looked at independent living and mentally retarded persons. Other populations examined include persons who are deaf (Petal, 1980), elderly (Williams, 1981), and learning disabled (Brown, 1984), and who live in rural areas (Richards et al., 1984; Richards, in press). For persons with mental impairments the key focus has been movement from large institutions to smaller community-based settings. A discussion of this parallel trend to the independent living movement follows.

IV. INDEPENDENT LIVING FOR PERSONS WITH MENTAL RETARDATION

The needs and potential of persons with mental retardation have been thoroughly researched and documented. The system for providing these persons with services is the most extensive and well funded in the field of disability. It consists of an intricate continuum of living arrangements, including multipurpose long-term care institutions, special purpose institutions, intermediate care institutions, a range of group homes and boarding homes for sheltered care, foster homes, and private homes (Braddock, 1978). However, only a portion of this system could qualify as independent living support services according to the above definition.

Sigelman and Parham (1981) cite the decrease in public residential facility populations and the increase in the number of smaller and more homelike community residential facilities as a move toward independent living support services for persons with mental retardation. They claim that the only common denominator of these facilities is the provision of a place to live and supervision; otherwise they differ widely in size, training goals, level of funding, and so on. In a national survey, O'Connor (1976) was able to identify 611 community residential facilities for developmentally disabled persons, most only recently opened. Using a somewhat less restrictive definition of a community residential facility--excluding only family care and foster care arrangements, facilities not licensed or contracted as mental retardation service providers, and apartment programs with no live-in staff--a more recent national survey uncovered 4,427 community-based residential facilities serving a total population of 76,250 (Bruininks, Hauber, Kudla, 1980). Over half of the facilities had opened between January 1973 and the time of the survey in June 1977.

Clearly, then, the deinstitutionalization movement has made rapid progress, and community residential facilities today represent a major option for many retarded persons who could not easily live on their own. According to the survey of Bruininks et al. (1980), approximately a third of the residents came to their facilities from institutions, but almost as many (32.4%) came from their natural homes. The remainder had entered their community residential facilities from other residential settings. These findings indicate that such facilities are also meeting needs among persons who, while never institutionalized, require more training and support than their own families can provide, especially when they reach adulthood.

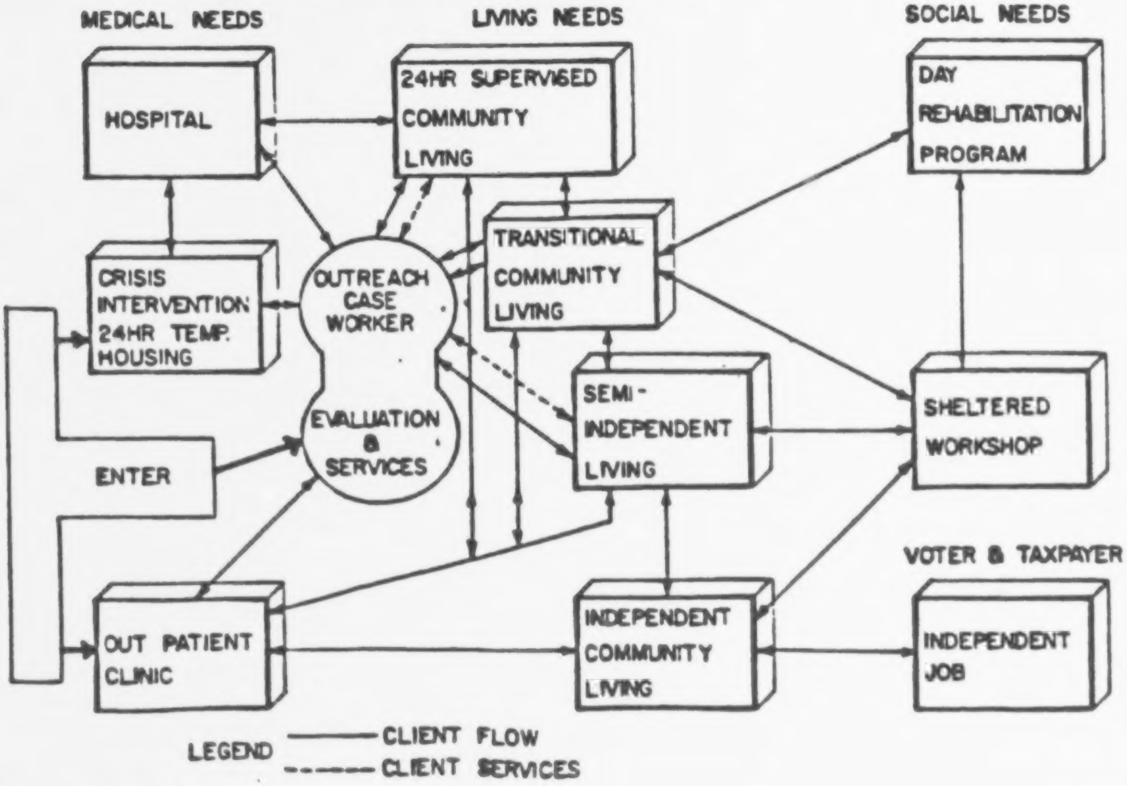
About 62% of the residents of community residential facilities are 22 years old or older (Bruininks, Hauber, and Kudla, 1980), and the vast majority are in some productive activity in their communities. According to O'Connor's 1976 survey of community residential facilities, about 9% of the residents were competitively employed; 48% were in workshops or training programs; 31% were in school; and 8% were in some other major day activity. Only four percent were without such major activities. These individuals, then, are active in the community and yet display widely different degrees of competency. Moreover, residents are drawing on the whole range of services available in the community, for it would be contrary to the purpose of small, homelike facilities to have all services provided in-house as they are in large institutions (Sigelman & Parham, 1981).

V. INDEPENDENT LIVING FOR PERSONS WITH MENTAL ILLNESS

In the interval between 1970 and 1982, several changes have taken place in the number of organizations constituting the nation's organized specialty mental health service delivery system. The total number of organizations that provide mental health services rose from 3,005 to 4,302 between 1970 and 1982, an increase of 43 percent. Despite the increase for all organizations combined, the number of State and county mental hospitals decreased from 310 to 277 in the same time period. Represented in these total figures are private psychiatric hospitals, non-Federal general hospitals with separate psychiatric services, residential treatment centers for emotionally disturbed children, and freestanding psychiatric outpatient clinics. Within specialty mental health organizations, a variety of different types of services are provided. Among the principal services are inpatient, outpatient, and day treatment care (Manderscheid et al, 1985).

As diagrammed on the next page by the Texas Alliance for the Mentally Ill, the full spectrum of service needs for this population includes far more than inpatient, outpatient, and day treatment care. Dramatic pharmacological, social, and legal changes have shaped community living programs for persons with chronic mental illness. In the 1950's, a revolution in the care of these individuals was made possible by the discovery of antipsychotic medications, under which previously disoriented persons demonstrated a renewed capacity to care for themselves. This, then, set the stage for the possibility of community care

TEXAMI PLAN FOR MEETING NEEDS OF CHRONICALLY MENTALLY ILL


MEDICAL NEEDS
LIVING NEEDS
SOCIAL NEEDS
HOSPITAL
24HR SUPERVISED COMMUNITY LIVING
DAY REHABILITATION PROGRAM
CRISIS INTERVENTION 24HR TEMP. HOUSING
OUTREACH CASE WORKER
EVALUATION & SERVICES
TRANSITIONAL COMMUNITY LIVING
SEMI-INDEPENDENT LIVING
SHELTERED WORKSHOP
ENTER
VOTER & TAXPAYER
OUT PATIENT CLINIC
INDEPENDENT COMMUNITY LIVING
INDEPENDENT JOB
LEGEND
CLIENT FLOW
CLIENT SERVICES

for persons who had been receiving only minimal care in large public hospitals.

About the deficits of the traditional large public psychiatric hospitals there was considerable agreement: they were too large, limited by a universal medical model, and functioned as a closed society--isolated, like a penitentiary, from society at large. Community residences, by contrast, were to be small, family-modeled living arrangements, functioning as open social systems, which existed within, rather than isolated from, the community. These new facilities survived and began to proliferate. In 1960, there were only seven professionally conceived programs in the entire country; by 1973 there were 209; and there are many more now.

The proliferation of these models has been given enormous impetus by court decisions of the 1970's. In addition, the large institutions, the local communities, and the State governments have all been affected by these judicial decisions. A tragic irony, however, is that these judgments in the name of patients' rights too often had the effect of forcing many patients into the community before adequate rehabilitative facilities were there to receive them (Budson, 1979).

In the space of three decades, powerful medical, social, and legal forces have moved the locus of treatment for persons with severe mental illness from the state hospital to the community. Attempts to reform the old custodial system have produced in their turn a complex and often contradictory set of demands that these people not be incarcerated without treatment; that these people not be released into the community before adequate community care programs exist; that large, expensive institutions not continue to drain dwindling State coffers; that unscrupulous private enterpreneurs not victimize again the vulnerable population of discharged patients (Budson, 1979).

The past decade of intensive development has, indeed, produced a broader spectrum of community care facilities. These facilities vary not only in function and philosophy, but often, unfortunately, in quality of care as well. At least ten different types of housing are currently in use in the United States: 1) transitional halfway houses; 2) long-term group residences; 3) cooperative apartments (satellite housing, landlord supervised apartments, post-halfway house accommodations); 4) lodge programs; 5) total rural environments (work camps); 6) foster care (family care); 7) crisis centers; 8) nursing homes; 9) board-and-care homes; and 10) hotels.

The National Institute of Mental Health has defined the transitional halfway house as a "residential facility in operation seven days a week with round the clock supervision (often a staff member living on the premises) and providing room, board, and assistance in the activities of daily living." Non-profit, private corporations usually operate these facilities in large old houses with 15-20 residents who generally participate daily in a planned program outside the dwelling.

Although the long-term group residence resembles the transitional halfway house in many particulars, its residents are usually sufficiently lacking in living skills, or sufficiently symptomatic, to require a higher onsite staff/resident ratio.

Cooperative apartments are distinctive in that they have no onsite staff and are usually comprised of groups of two to four per unit. There is a regular staff visit from the sponsoring mental health agency to oversee the living arrangement as well as the required outside daily program. Cooperative apartments are often developed as outward community extensions or satellites of staffed residential programs.

Total rural environments are nonhospital residential facilities which offer total supervised living including daily on-premises farming chores. The focus is that of an operational farm which provides ongoing reality-based responsibilities with high attention to the fulfillment of rehabilitative goals.

Foster or family care, one of the oldest community placements, entails the location of ex-patients in private homes. Up to four residents may be placed in one foster home. The individual is supervised by the family caretaker who is in turn supervised by a visiting social worker from the referring institution.

Nursing homes are a major community residential site to which thousands of chronically mentally ill persons who are elderly or physically handicapped are sent. The nursing home was one type of supervised residential facility which was readily available when the pressure to discharge patients mounted.

A "crisis center" is an alternative residential facility which allows the individual to leave a noxious home situation without having to go to a psychiatric hospital. Such a facility has a higher staff/patient ratio, is small, and has a capacity for around-the-clock care.

Board-and-care homes have been the recipient of uncounted numbers of discharged chronic patients. Their use has stimulated much controversy. These are generally proprietary rooming houses which provide a wide range of care, depending upon the interest and motivation of the proprietor (Budson, 1979).

Although the range of living options for persons with mental illness appears to be broader than that available to persons of different disability groups, it is in fact very limited. Eligibility for residence in certain facilities is restricted to those recently in larger institutions, in effect requiring hospitalization prior to community living. Many facilities will not accept persons who have visual, hearing, or mobility impairments in addition to mental illness due to a lack of personal assistants (readers, interpreters, attendants), and architectural inaccessibility. Availibility of space in any of these options, let alone those with progressive, independence oriented programs, is grossly inadequate given the enormity of the population in need.

VI. THE NEED FOR INDEPENDENT LIVING RESEARCH, EDUCATION, AND PROFRESSIONAL TRANINING

There is general concensus that training for independent living must begin as soon as all children first enter school. For children with disabilities, special independence-oriented education should start from birth to counteract the effects of negative attitudes toward disability and other barriers in society. Education systems should be required to give all students the opportunity to understand the reality of disability and the abilities of persons with disabilities. This will prepare everyone for the inevitable onset of disability at some point in their life and help eradicate barriers to equal opportunity.

If such education is to be offered to the general public with specialized education offered to persons with disabilities and their families, curricula must be developed and specialists in this area must be trained. Pre-service training for professionals in education, medicine, and other disability-related fields should be required to include the study of independent living needs of children and adults with disabilities.

The quality of training for the professionals who will strongly influence the lives of persons with disabilities will reflect the state of the art in research related to independent living. Currently, the state of the art in this area is embryonic. Independent living services have for the most part responded to the constraints imposed by existing systems, and have been developed by trial and error. Very little empirical, valid research underlies the provision of community-based services for independent living. Most current research supports services for mental impairment rather than for physical impairment.

At the present time, two research and training centers in independent living are funded by the National Institute for Handicapped Research. Some grants have been given by the Rehabilitation Services Administration to improve the delivery of services by centers for independent living, and by the Office of Special Education to develop curricula for independent living skills training as part of the transition from school to work and life in the community. However, these efforts are miniscule compared to the grant potential within the Department of Education.

There must be a better understanding through controlled research and development activities of what independence is and how the independence of persons with disabilities can be developed and enhanced. There should be ongoing scientific efforts to gather and analyze data on the independent living needs of the disabled population; to evaluate methods for meeting those needs; to provide technical assistance to providers of independent living support services and those who wish to initiate such services; and to explore and demonstrate innovative methods, including the use of technology, for delivering independent living services and living independently for persons with all types of disabilities.

VII. EXPENDITURES, COSTS AND BENEFITS

In analyzing current expenditures for independent living and what has been called long term care services, it is necessary to consider the expense of not providing independent living support services, i.e. institutionalization, as well as the expense of operating community-based programs. Following is a discussion of expenditures for long term care facilities and services, intermediate care facilities, community-based residential facilities for mentally impaired individuals, and community-based independent living programs. It is followed by a discussion of the costs and benefits associated with community-based independent living services.

A. Expenditures

It is difficult to estimate total public and private expenditures for long term care services. According to the National Study Group on State Medicaid Strategies (1983), about 60 to 80% of elderly people's long term care is provided by friends, neighbors, and relatives, with no remuneration. This figure is probably equally applicable to younger disabled persons. The primary source of public expenditures for long term care is Medicaid, which in 1981 accounted for $12.4 billion, or 81% of public long term care expenditures. The bulk of public and private long term care expenditures pays for nursing home care, which is the third largest and one of the fastest growing areas of national health expenditures. Between 1965 and 1978, the growth in nursing home expenditures averaged 16.9% per year, increasing from $2.1 billion to almost $16 billion. (Of the 1978 total, 53% came from public and 47% from private funds, mostly out of pocket payments.) This figure is expected to double in 1985 and reach $76 billion by 1990 (Freeland, Calat, and Schendler, 1980). The National Center on Health Statistics data show that 12.6% or more than 174,000 of the residents in nursing homes are under age 65 (Sirrocco, 1985).

Medicaid financing paid primarily for skilled nursing and intermediate care facilities in 1981 ($12.3 billion). Of this amount, just $146 million or 1.2% was spent on home health care, primarily in New York and California. Medicaid skilled nursing facility and intermediate care facility payments have grown at an alarming rate. In response to rising institutional care costs, Congress -- in Section 2176 of the Omnibus Budget Reconciliation Act of 1981 -- authorized waivers to allow State Medicaid programs to expand the provision of home and community-based services as an alternative to institutional care. Because these initiatives are just beginning, they are not reflected in expenditure data or budget projections. A small but growing category of Medicare reimbursements covers some post-hospital nursing care as well as home health visits.

Other public long term care funding is available from the Veterans Administration and under the Older Americans Act, Title XX of the Social Security Act, and the Housing Act of 1959. (Title XX long term care expenditures are no longer separately measureable because of the 1981 conversion to block grant funding.) Another source of Federal and State financing is SSI supplemental payments for domiciliary and other residential care facilities.

The Title XIX Immediate Care Facilities For the Mentally Retarded (ICF/MR) program is the major Federal source of funding for both institutional and community care of persons with mental retardation. In Fiscal Year 1985, it accounted for 34.2% of a total of $7.773 billion in Federal spending for mentally retarded and developmentally disabled persons (Braddock, Hemp & Howes, 1985). To gain perspective on the significance of Social Security as a source of revenue, it is useful to observe that of the total Federal expenditures in the area of mental retardation in Fiscal Year 1985, Supplemental Security Income (SSI) payments to persons with mental retardation constituted 19.7% of total Federal spending in this area in Fiscal Year 1985; Social Security Disability Insurance (SSDI), 16.4 %; noninstitutional Medicaid expenditures, 12%; and Title XX social services, 2.8%.

The growth of Federal reimbursements for institutional care of mentally retarded persons since 1977 has been explosive (Conley & Noble, 1985). The Federal share of expenditures for State institutional services has increased from 23% to 45%, rising from $570 million in 1977 to $1.9 billion in 1984. Although the Federal share of expenditures for community services increased significantly, from $45 million (6%) in 1977 to $663 million (21%) in 1984 today the amount spent on community services is less than a third that spent on institutional services.

According to Conley and Noble (1985), the Title XIX ICF/MR program has a strong institutional bias that is sometimes reinforced by funding arrangements between State and local governments. Where local governments do not share in the cost of community-based services, there is a strong incentive to avoid developing community alternatives to institutional care for persons with mental retardation.

A compilation of all public funds spent for mentally retarded persons in 1981 was done by Smith (1984):

Total funding (in billions)		$11.7
Source of funds		
Federal	$5.4	
State	$6.3	
Expenditures		
Residential care		$5.9
institutions	$ 3.7	
community facilities	$ 0.7	
other long-term care	$ 1.1	
miscellaneous	$ 0.4	
Community-based support services		$4.5
SSI/SSDI and State grants to counties		$1.3

Smith further lists per diem estimates for various residential settings based on a report of the Department of Health and Human Services Inspector General in 1981:

ICF/MR (institution)	$80/day
ICF/MR (community)	$65/day
Non-ICF/MR group home	$50/day

These group homes are financed with the residents' SSI/SSDI payments, State funds, Section 202 loans and Section 8 rent supplements from the Department of Housing and Urban Development, food stamps, parent/resident fees, and voluntary sector contributions.

Wieck and Bruininks (1982) present a per diem reimbursement rate according to facility size categories. Public residential facilities with fewer than 500 residents reported the highest per diem of $60.05. Lower per diems were reported for larger facilities: $41.68 for facilities with 500-999 residents, $47.81 for facilities with 1,000-1,599 residents, and $46.82 for facilities with more than 1,600 residents. In contrast, community residential facilities showed a steady progression in per diem rates, with the smallest facilities having the lowest per diem ($15.51) and the larger facilities reporting higher per diems ($25.09).

Size of Public Residential Facilities	Average Per Diem
<500	$60.05
500 - 999	41.68
1,000 - 1,5999	47.81
1,600+	46.82

Size of Community Residential Facility	Average Per Diem
1 - 5	$15.51
6 - 15	16.40
16 - 32	18.86
33 - 64	25.50
65+	25.09

In the area of mental health, expenditures for the provision of services rose dramatically in the 1970's. Frank and Kamlet (1984) discuss these expenditures in three categories according to the locus of mental health care:

- The specialty mental health care sector, which includes State mental hospitals; community mental health centers; office-based psychologists, psychiatrists, and social workers; and general hospital psychiatric units.
- The general medical sector, which includes psychiatric services in general hospitals outside of psychiatric units, nursing homes, and nonpsychiatrist physicians.
- The human service sector, which includes schools and the criminal justice system; and the nonhealth sector, which includes transportation services for treatment of mental disorders, expenditures by the Social Security Administration for the maintenance of mentally disabled individuals, and expenditures made under Title XX.

The estimated total direct costs for mental illness in 1980 were between $17.2 billion and $19.9 billion. When estimated transfer payments were added, the range was between $19.4 billion and $24.1 billion. The high estimate of direct costs represents 7.7% of total expenditures on health care for the nation in 1980 (Hodgson & Kopstein, 1984). These figures also imply that direct costs of mental health care comprised approximately 0.65% of the Gross National Product in 1980. The total direct costs were incurred as follows (Frank & Kamlet, 1984):

SECTOR	AMOUNT (billions)	PERCENT
Specialty mental health	$10.7	53.6
General health	$ 6.1	30.6
Human services and nonhealth sector	$ 3.1	15.8

Social Security Disability Insurance payments made to individuals with mental illness (excluding alcoholism, drug dependence, and alcoholic psychosis) in 1980 were estimated to total $1.8 billion based on data from a survey conducted in 1976. Applying a similar methodology for payments to spouses and children of mentally ill workers, a total figure for 1980 of $4,089 million is estimated.

The annual real rate of growth in direct costs of mental health care is estimated to be 1.7% between 1977 and 1980. Comparison with the rate of growth (3.6%) in the general health sector for direct costs of health care as a whole indicates that the real claims on resources made by the mental health sector are decreasing relative to those made by all health care (Frank & Kamlet, 1984).

In contrast to the wealth of literature on spending in the areas of mental retardation and mental illness, studies of the cost of independent living services for all other disability groups are scant. The Rehabilitation Services Administration reported in 1983 that the $19.4 million appropriated under Title VII Part B funded in whole or in part 156 centers for independent living which delivered services to 26,000 severely disabled people, 69% of whom had physical disabilities.

It is clearly evident that funding for institutionalization of disabled people far outweighs funding for independent living. Even among the programs operated for mentally retarded and mentally ill persons which are established as community-based centers, few truly focus on maximizing self-determination and eliminating unnecessary dependence on others to the extent of one's potential. The question at hand, then, is not one of limited resources; it is one of orientation, priority reassessment, and funding reallocation to support community-based independent living services. When such services are in place, most persons currently living in institutions can be served in the community.

B. Costs/Benefits of Community-Based Services for Independent Living

Analysis of the economic benefits resulting from the availability of community-based services for independent living is extremely complex and confounded by the highly individualized nature of disability and personal support systems. The provision of Federal funding for personal assistance, subsidized housing, and other support services does not guarantee that the individual will become gainfully employed and become a taxpayer instead of a tax-user. Indeed, under the present system, by becoming employed, individuals become ineligible for the benefits which made them employable. Yet economic benefits do exist. These are best illustrated by individual case studies:

> Mary had a stroke with moderate speech involvement and uses a walker. She receives SSI, Medicaid, subsidized housing benefits, food stamps, a utility subsidy, and weekly homemaker services which cost approximately per month. She uses a public paratransit system for mobility in the community; however she can rarely get reservations for the times she needs or wants to travel. Although Mary has a master's degree in social work, she is unable to secure employment due to doubts expressed by interviewers about her ability to communicate with clients. If employers were more aware of ways to tap Mary's abilities through job modifications and technology, and if reliable, accessible public transportation were more available, she could be earning a salary of $1,200 to $1,500 per month.
>
> James has lived in a State school for persons who are mentally retarded for 34 of his 40 years at an average cost to the Federal and State government of $2,400 per month. He has severe cerebral palsy and uses a power wheelchair. He also has a learning disability. James is outgoing and frequently participates in community advocacy activities. He spent a year in the transitional living house run by the local center for independent living. He now lives in the community in an apartment with two students referred to him by the center for independent living. They provide for his personal assistance and housekeeping needs. He receives an array of benefits similar to Mary's, valued at approximately $1,000 per month. Next fall, he hopes to be sponsored by the State rehabilitation agency to attend classes at the community college. He plans to obtain a high school equivalency degree and seek training and employment as a computer operator.

VIII. RECOMMENDATIONS

The Council has defined independent living as "control over one's life based on the choice of acceptable options that minimize reliance on others in making decisions and in performing everyday activities" (National Policy for Persons with Disabilities, 1983). Living independently includes managing one's affairs, participating in the day-to-day life of the community in a manner of one's own choosing, fulfilling a range of social roles including productive work, and making decisions that lead to self-determination. Community-based services that promote such independence for Americans with disabilities constitute one of the most promising service delivery strategies for our Nation.

The Council wishes to affirm that the independent living philosophy and a preference for community-based services should permeate the services and benefits supported by the Federal Government. The goal should be to establish core funding for a continuum of community-based services guided by independent living concepts.

In order to live independently, disabled persons require a wide range of support services according to their disability type. Persons with severe physical disabilities usually require assistance with personal care, domestic tasks, transportation, equipment maintenance, and modifications of home and work place for architectural accessibility. Those with sensory disabilities may require assistance with interpersonal communication such as that provided by readers and interpreters. Persons with mental impairments who wish to live independently may require some degree of supervision and assistance with cognitive tasks. All persons with disabilities and their families can benefit from a single source of information and referral about services and service providers.

In 1978, Congress incorporated a program of Comprehensive Service for Independent Living in Title VII of the Rehabilitation Act. It was the first Federal legislation to specifically authorize funding for services needed by people with such severe disabilities that they do not presently have the potential for employment. It permits services to be provided to those presently without employment potential if they may benefit from vocational rehabilitation services (authorized under Title I, Part A) which will improve their ability to engage in employment or to live and function independently in their families or communities. Part A of Title VII authorizes payments for independent living services that are provided under approved State Plans. Part B authorizes a grant program for the establishment and operation of independent living centers that offer, among other services, the services funded under Part A. Part C authorizes funds to provide independent living services for elderly blind individuals.

Funding for independent living services under Title VII is very limited when compared to Medicaid (Title XIX of the Social Security Act) funding for institutional care for people with severe disabilities. If community-based independent living is to become a realistic goal for Americans with severe disabilities, the institutional bias within Medicaid and other programs funded under the Social Security Act must be replaced by a preference for community-based services.

1. Congress should require the agency in each State designated to administer Title VII, Part A of the Rehabilitation Act to allocate no less than 50% of available funds to purchase services from independent living centers that meet the standards approved by the National Council on the Handicapped. No more than 10% of available funds should be used for administrative purposes. The remaining funds should be used at the discretion of the administering agency in any way that assists people with severe disabilities to achieve independence and productivity in their communities.

Currently States are required to provide assurances in their State Plans that no less than 20% of the funds received by a State under Part A are used to make grants to local public agencies and private nonprofit organizations for the conduct of independent living services (unless a waiver of this requirement is obtained from the Commissioner of the Rehabilitation Services Administration). The Council recommends that this percentage be increased to 50% to assure that funding for independent living services is available to and provided by agencies established and operated for this purpose under Title VII, Part B. Such funding for services should be authorized only for independent living centers that comply with the standards approved by the Council.

Coordinated services are essential to the ability of a person with a severe disability to live in the community. Therefore, the Council recommends that States applying for Part A funds be required to submit a plan for the coordinated delivery of services, including personal assistance services (attendants, readers, interpreters, and advocates for mentally retarded persons); and accessible housing and transportation; and for State-wide information and referral services for all people with disabilities and their families. Administrative expenses for arranging services should be strictly limited to 10% of these funds.

The Council recommends that funding for Part A be continued as a means of ensuring that community-based services are made available to persons with severe disabilities. Its implementation should include requirements that independent living facilities and services comply with standards approved by the Council for program administration, service delivery, and program evaluation.

2. Congress should provide core funding under Title VII, Part B of the Rehabilitation Act, for independent living centers that meet the standards approved by the National Council on the Handicapped. Such centers should be allowed to apply and compete for this funding on an equal basis with State vocational rehabilitation agencies.

Community-based, consumer-controlled independent living centers were created to assist persons with severe disabilities to increase their level of independence. As defined in Title VII Part B of the Rehabilitation Act, these centers must significantly involve disabled persons in policy direction and management, and must offer a combination of independent living services. Part B of Title VII, which funds over 150 of these centers nationwide, should be used as an ongoing source of funding to support the start-up of new centers and to provide core support for established centers, whether or not these centers have received Title VII funding in the past. At least 20% of Part B funds should be used to support the establishment of new independent living programs, with an emphasis on rural and other underserved areas. The remaining available funds should be used for core support of established centers.

The standards adopted by the National Council in 1985 for evaluating independent living centers should be enforced as a prerequisite for the distribution of funds. New centers which do not meet the standards at the time they apply for Federal funding should be required to follow a pre-application process and have a plan to meet the standards before receiving Federal funding. In addition, independent living centers should be strongly encouraged to obtain funding from other public and private sources. All centers should include representatives of the business community on their boards of directors. A mechanism should be established to provide incentives for States to match Federal efforts for independent living centers.

The Council wishes to note that in requiring independent living centers to be consumer-controlled, it defines "consumer" as including persons with all types of disabilities. It believes that those with mental retardation or a history of mental illness, for example, can serve a vital role as consumer members of boards or in other responsible positions.

3. Congress should require the Health Care Financing Administration to study the institutional bias within its programs for persons with disabilities and to develop appropriate measures for eliminating such biases. The criteria should be developed in consultation with the National Council on the Handicapped and be reported in hearings before Congress within one year from the date of enactment of this requirement.

An extraordinary amount of the Medicaid funds administered by the Health Care Financing Administration (HCFA) is spent on nursing homes and other long-term institutions that primarily provide custodial maintenance for disabled individuals. The Council believes that strictly maintenance-oriented institutional programming is indefensible and unnecessary. Wherever possible, institutions should be transitional and foster independence. The majority of available funding should be directed toward assisting all individuals with severe disabilities to achieve self-direction and independence to the maximum of their potential, in the most dignified and least restrictive enviornment.

The Council recommends that Congress require HCFA to develop, posthaste in consultation with the National Council on the Handicapped, criteria to be used to determine to what extent Medicaid and other programs administered by HCFA promote community-based services and discourage placements in institutions. Programs that serve people with disabilities should be assessed using these criteria, and the resulting report should be used as a basis for making fundamental changes in the management and structure of these programs. The Council recommends that the Congress hold hearings within one year of the enactment of this requirement to review HCFA findings and plans for action.

The evaluation criteria should include a focus on the following topics:

- o Comprehensive personal assistant services, including long-term, short-term (respite), and emergency attendants, readers, interpreters, and advocates for mentally retarded people.
- o Case management assistance for independent living, including transition services from the hospital to the home, institution to community, and from parents' home to independence in the community; and assistance in

equipment selection and maintenance, and in locating sources for other independent living support services.

- Family support and consumer education services, including financial and personal counseling and training in self-directed and family-provided home care, including the use of equipment and medication, and independent living skills training.
- Habilitative and rehabilitative training, including prevocational services.
- Comprehensive medical insurance for disabled persons who are unable to obtain adequate insurance through their employers or who are ineligible for other Federal medical benefits.

4. Congress should amend the Internal Revenue Code to establish a tax credit for taxpayers with disabilities who incur unreimbursed expenses directly related to independent living, employment, and efforts to secure employment, including personal assistant services, special transportation, assistive devices, and other support services.

This recommendation is made as a partial means of removing the disincentives to work which are inherent in the Social Security system. While certain tax deductions are currently allowable under a medical categorization, the regulations are unclear regarding nonmedical, disability-related services which enable the individual to work or engage in productive activity. Such expenses, up to a reasonable amount for each type of expense, should be made deductible.

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TOPIC PAPER H:

EDUCATING CHILDREN WITH DISABILITIES

National Council on the Handicapped

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ACKNOWLEDGMENT

This is one of a series of ten topic papers developed by the National Council on the Handicapped as part of its Special Report to the President and Congress: TOWARD INDEPENDENCE: An Assessment of Federal Laws and Programs Affecting Persons with Disabilities--With Legislative Recommendations. The members of the National Council on the Handicapped wish to expressly acknowledge with appreciation the special contribution made to this paper by Michael Marge and Naomi Karp.

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I. INTRODUCTION

With the enactment of Public Law 94-142 approximately ten years ago, a new era of educational and civil rights dawned in the United States. The purpose of the legislation was to ensure that every handicapped child between ages five and eighteen, and later between three and twenty-one years of age, receive appropriate public education in the least restrictive environment. There is substantial evidence that this legislation has had a very positive effect on the educational process and philosophy of our nation. The legislation has made it possible for over four million children with all types of special need to receive educational and related services in 1983-84 (U.S. Department of Education, 1985).

This legislation has also provided opportunities for children without disabilities to learn with and from their peers who are disabled. Several committed school districts have developed carefully planned, totally integrated programs that allow severely disabled students to attend regular schools with their nondisabled peers, preparing them to fully participate in community life together.

There is, however, considerable need for further progress in providing appropriate and qualitative educational services to disabled infants and children. The National Council on the Handicapped has identified three specific issues pertaining to the educational needs of children with disabilities that require the immediate attention of Federal, State and local law-makers. The three issues are:

1. The need for federally-mandated special education and related services beginning at birth. Every State should provide these services to infants and young children with special needs to ameliorate and deter the effects of congenital and early acquired impairments and disabilities. If such impairments and disabilities are unattended, they will lead to staggering costs in later years.

2. The need to assure that children with special needs are educated in the same school buildings as their nondisabled peers. Only by placing students of all ages and ability levels in non-restrictive environments will these students become adults who possess the skills and behaviors needed to fully participate in society. Also, their nondisabled peers will consider it routine to work and participate in leisure activities with persons with disabilities, thereby ameliorating attitudes that create the counter-productive and costly barriers that reduce opportunities for people with disabilites.

3. The need to establish a National Commission for the Study of Excellence in Special Education. The Commission should study the current status of educational programs and related services for our nation's handicapped children and youth. It will identify positive contributions, describe shortcomings, and recommend methods to improve services for disabled children.

II. EARLY CHILDHOOD AND PRESCHOOL PROGRAMS FOR CHILDREN WITH SPECIAL NEEDS

A review of the effectiveness of preschool education for children with handicapping conditions has demonstrated definite educational and economic benefits. It has become clear that the earlier the intervention, the greater the ultimate dollar savings and the higher the rate of educational attainment in subsequent years (Select Committee on Children, Youth, and Families, 1985). In this August 1985 report released by Congressman George Miller (D-CA) and Dan Coats (R-IN), eight Federal programs were analyzed to show: 1) how they improve the lives of the children involved and 2) how they saved tax monies. The report provided the following support of the importance and benefits resulting from early intervention programs for disabled infants and young children:

- o If intervention for handicapped infants is delayed until age 6, special education costs to age 18 are estimated at $53,350. Intervention at birth is estimated to result in special education costs of $37,272, a savings of $16,078.
  - For every $1 invested in high quality preschool programming, there is a $3 reduction in public special education costs.
  - School districts in Colorado have saved $1,560 per pupil in special education costs because of the INREAL early intervention program (Select Committee on Children, Youth, and Families, 1985, p. 27).

A. Federal Legislation

Other studies support the finding that children enrolled in early intervention programs had less need later for special education programs than their counterparts who did not receive the interventions. In the U.S. Department of Education's Seventh Annual Report to Congress (1985), Schweinhart and Weikart projected that if a child receives preschool interventions, there will be a 248% return on the investment by the time high school is completed. Witnesses at a series of public hearings on education issues pertaining to all American children testified that "The major finding across studies is that early childhood education reduced the need for special education placement and retention in grade." (National Coalition of Advocates for Students, 1985).

Two Federal programs currently provide support for early childhood education services. They are described below.

1. Handicapped Children's Early Education Program--Part C, Section 623. In 1970, Public Law 91-230 established the Handicapped Children's Early Education Program (HCEEP), often referred to as the "First Chance Network." The program encouraged the development and dissemination of models for delivery of services to young children with special needs. Public and private nonprofit agencies were supported in developing and demonstrating top quality service programs for disabled children and their families. Many of the effective models were then disseminated throughout the country.

Public Law 98-199 introduced a major change in the Handicapped Children's Early Education Program (HCEEP). The new amendments to P.L. 94-142 mandate State-level comprehensive service delivery systems, thus altering the State Implementation Grant (SIG). The SIG was designed to assist State education agencies to plan for the development and expansion of early intervention services for young children with special needs. These grants provided administrative resources rather than direct services to children. But with the passage of P.L. 98-199, the Early Childhood State Plan program replaced the State Implementation Grant Program. Under Part C, Section 623, awards are now made to States to plan, develop, and implement a comprehensive statewide plan for delivering special education and related services to young disabled children from birth through five years of age. Priority emphasis is on children who often are not identified and who are not now served. The legislation encourages parent participation in the development and operation of programs that are designed to improve language, social, physical, mental and emotional development of young children with special needs.

State plan grants are awarded to State education agencies for three phases of activities that focus on planning, development, and implementation:

(a) Planning grants are available for up to two years. The range of funding for planning grants is $70,000-$100,000 per year to assess the needs and put together procedures for the development of a State plan.

(b) Development grants are available for up to three years. The range of funding for development grants is $125,000 to $150,000 per year to develop a comprehensive State plan and obtain State agency approval.

(c) Implementation grants are available for up to three years. The range of funding is $180,000 to $220,000 per year.

Commencing in 1986, a description of the status of special education and related services to disabled children from birth through five years of age shall be included in the Secretary of Education's Annual Report to Congress. This will require documentation of the number of young children receiving services through Head Start, Developmental Disabilities Program, Crippled Children's Services, Mental Health/Mental Retardation Agencies, and State Child Development Centers and private agencies under contract with local schools. It is hoped that this effort will result in better coordinated services at the local and State levels.

The new State plan grant program affords States the opportunity to build a comprehensive service program for all disabled and at-risk children from birth to five years of age. The goal of the Federal Office of Special Education (within the Department of Education) is that every State and Territory will apply for a State plan grant within the next few years.

2. Preschool Incentive Grants. Funds obtained under the Preschool Incentive Grant Program are used by States to provide special education and related services to handicapped children, ages three to five. A formula is used to determine how much funding each State will be awarded for the provision of these services.

With the enactment of P.L. 98-199, Section 619(c), the Secretary of Education shall provide funds for special education and related services to handicapped children from birth through three years of age.

In Fiscal Year 1985, 55 of 57 eligible agencies elected to participate in the program. The funds available for this program increased from $12,500,000 in Fiscal Year 78 to $29,000,000 in Fiscal Year 85 (U.S. Department of Education, 1985).

States report that the Preschool Incentive Grant Program has made an impact on the overall services to young handicapped children as follows:

(a) Identification and assessment procedures have been refined.

(b) More effective training is available for personnel who provide services to handicapped children.

(c) The capability of local educational agencies to meet the individual needs of handicapped children aged birth through five has increased.

(d) Rural service delivery programs have been expanded for handicapped children from birth to five years of age.

(e) Dissemination of information on available services for young children has increased.

(f) Services to the population from birth through two years of age have been expanded (U.S. Department of Education, 1985).

B. Number Served

Currently, 42 States mandate services to some portion of the birth through five year old population with special needs. Only seven States mandate services beginning at birth. Nineteen States mandate services for all three to five year olds with disabilities, and twenty-three mandate services for some portion of the three to five year old population. These data are summarized from the chart on the following page.

The Federal Office of Special Education Programs estimates that approximately 250,000 children from birth to two years of age are in need of special education services. However, only 60,000 of these children are receiving the necessary services (Conversation held with Becky Calkins, 1985).

C. Gaps in Legislation

States report that several Federal initiatives resulting from the amendment of the Education of the Handicapped Act by Public Law 98-199 helped both State and local education agencies to improve and increase services to preschool handicapped children. These include changes in the use of the Preschool Incentive Grant Program to allow services down to birth, the State Implementation Grant Program, and a variety of other programs under the Handicapped Children's Early Education Program (U.S. Department of Education, 1985). In many States, the Support for State Operated and State Supported Schools Program authorized by Public Law 89-313, Part B is being used to improve the quality of early intervention services and to extend service delivery.

PROFILE OF STATES' MANDATED AGE OF ELIGIBILITY FOR PRESCHOOL ELEMENTARY SCHOOL SPECIAL EDUCATION SERVICES

Mandated Service from Age	
0	Iowa-Maryland-Michigan-Nebraska-New Jersey-South Dakota
2	Virginia
3	Alaska-California-Connecticut (from 2.8 years)-Hawaii-Illinois-Louisiana-Massachusetts-New Hampshire-Rhode Island-Washington**-Wisconsin-Texas* (from birth for VI, HI, and DB)
4	D.C.-Minnesota-Delaware* (from age 3 for TMH, SMH, and PI; from birth for HI, VI, DB and A)-Oklahoma* (from birth for VI, HI, and severely handicapped)-Tennessee* (from age 3 for D)
5	Colorado-Florida-Georgia-Idaho-Kentucky-Maine-Missouri-Nevada-New Mexico-New York-North Carolina-Ohio-Utah-West Virginia
6	Alabama-Indiana-Kansas-Mississippi-Montana-North Dakota-Oregon-Pennsylvania-Vermont-Wyoming-Arkansas* (from age 5 if LEA offers K)-South Carolina* (from age 4 for HI and D)

A = autistic
D = deaf
DB = deaf-blind
EMH = educationally mentally handicapped
HI = hearing impaired
K = kindergarten
LD = learning disabled
PH = physically impaired
SEM = socially/emotionally maladjusted
SI = speech impaired
SMH = severely mentally handicapped
TMH = trainable mentally handicapped
VI = visually impaired

* Exceptions to preschool age mandates (for example, in Texas all handicapped children age three and older are eligible for special education and related services; in addition, services are mandated from birth for all children who are visually impaired, hearing impaired or deaf-blind).

** Preschool services in Washington are currently mandated from age 5. In the 1984-85 school year, preschool services will be mandated from age 4 and in the 1985-86 school year, preschool services will be mandated from age 3.

NOTE: Alaska has moved to mandated services from birth.

SOURCE: Data obtained from SEAs and a review of the 1984-86 Annual Program Plans. Reproduced from the above referenced Special Net bulletin board with permission of the National Association of State Directors of Special Education (NASDE), 2021 K Street, N.W., Suite 305, Washington, D.C. 20006. (National Center for Clinical Infant Programs.)

A 1984 review of the State plans indicates that at least 18 States are using some portion of their set-aside funds available under the Education of the Handicapped Act, Part B (EHA-B) State Grant Program to expand preschool services. For example, EHA-B State Grant Program funds are being used to help finance the development of infant programs in Maryland, Florida, and California; the operation of Child Find Activities in Montana, Nevada, Pennsylvania, North Dakota, South Dakota, and Tennessee; the support of interagency activities and development of guidelines and handbooks for preschool programs in South Dakota; and the dissemination of information on the importance of early identification and intervention in Arizona.

Currently States may use a hodge-podge of Federal legislation to plan for and provide special education services to a portion of disabled children from birth to five years of age. A great deal of variability exists in the availability and quality of services for these children. And as was stated earlier, there is a critical need to provide services to the birth to two year old population since it is estimated that only one-fourth of this population receive needed services.

Several States are making considerable investments in developing comprehensive education services for disabled infants and young children. As an example, Massachusetts has developed a model that should be considered by States interested in meeting their responsibilities to the preschool handicapped population. In 1983, the Massachusetts Legislature passed a bill which structurally and programmatically altered the delivery of early intervention services to handicapped children between birth and three years of age. The bill designated a single State agency, the Department of Public Health, with responsibility for the provision of early intervention services, increased the resources available for the "systematic and rational" expansion of services, and directed the Department of Public Welfare to include early intervention services in its list of reimbursable services under Medicaid (Wyngaarden-Krauss, 1985).

Despite evidence of the benefits of early programming, State and local education agencies report three constraints on the ability of the States to obtain mandates for early childhood educational services, especially for handicapped infants. These constraints are: (1) limited fiscal resources at the local and State levels; (2) attitudes among many that young children should not attend school; and (3) disagreement concerning which agency should be responsible for serving preschool handicapped children. Continued progress in mandating early childhood educational services for handicapped infants and young children will depend in part upon the successful resolution of these three issues (U.S. Department of Education, 1985).

III. INTEGRATION OF SPECIAL EDUCATION CLASSES AND PROGRAMS INTO REGULAR EDUCATIONAL SETTINGS

Research documents that it is in the best interest of students, their families, and the public to house special education classes in regular school buildings with nondisabled children (Brown, et al., 1982). The integration of disabled and nondisabled children in the educational setting supports the goal of enabling disabled persons to fully participate in their communities' employment, social and recreational programs.

Research also supports the finding that integrated schools are cost-effective because of decreased costs for building maintenance, transportation, and other administrative and materials costs. Further, integrated schools are producing graduates who are better able to function in integrated post-school environments. Most significantly, student behaviors improve markedly in integrated settings. Nondisabled persons become more accepting of persons with disabilities when they are together in integrated buildings (Brown, et al., 1982).

Placing students with special needs in the least restrictive environment means that with proper technical assistance and careful planning, local school districts can establish integrated educational programs that are appropriate for a range of needs for all children. School districts in Albuquerque, New Mexico; San Francisco, California; Madison, Wisconsin; Birmingham, Alabama; and DeKalb, Illinois have established major integrated programs (Taylor, 1982). Parents, educators, and the general public must be willing to create programs that allow disabled children to be educated alongside their nondisabled peers if people with disabilities are to be prepared to fully participate in their communities as taxpayers rather than as taxtakers.

Congress did not specifically define "least restrictive environment" in either Public Law 94-142 or its amendments. However, many special educators and parents interpret "least restrictive environment" to mean that appropriate public education should be provided in regular school buildings, integrating handicapped and nonhandicapped children. In other words, programs should be tailored to meet individual special needs, while at the same time allowing disabled and nondisabled children to be together for as many appropriate activities as possible.

The trend toward integrated school systems is slowly growing, even among State-supported schools for students with special needs. For example, only 26% of elementary and secondary deaf students attended residential schools in 1984, as compared to 46% in 1970 (Will, 1985). Today, the vast majority of deaf students are successfully integrated into secondary schools with peers who are not deaf (Wicker, 1985).

It is essential that the Department of Education help States develop strategies for designing appropriate, carefully planned, fully integrated educational programs for students with special needs. Even though several school districts have model integrated educational programs, hundreds of other districts need technical assistance to help them develop similar programs. It is also very important that the Department of Education carefully review and monitor State special education plans to ensure that students are receiving services in the least restrictive environment.

In 1954, the Supreme Court ruled that "separate but equal" schools were unconstitutional. In 1986 and beyond, that ruling should apply to all educational programs for the handicapped.

IV. RECOMMENDATIONS

Special education helps this nation's children with disabilities to develop the skills they need to live as independently as possible when they become adults. Although special education services have progressed greatly since the passage of the Education for All Handicapped Children Act over ten years ago, the knowledge and ability to implement "best practices" falls short of what is needed.

First and foremost, there is a need to encourage the States to make available special education and related services beginning at birth. Of an estimated 250,000 children under the age of two who could use special education services each year, only 60,000 receive services. Just seven States mandate that special education services should be provided to infants. In addition, the availability and quality of services for young children with special needs varies greatly from State to State.

Educational services for infants are typically provided in the home, with educators and parents working together closely to enhance the child's educational development. Considerable evidence indicates that early intervention programs that actively involve parents result in greater ultimate educational achievement, improve the quality of life of disabled children and their families, and reduce the extent of need and therefore the cost of special education services in later years. As a result, early intervention services produce considerable tax savings over the long run.

A second critical issue is the need to educate children with special needs in regular education settings. Students of all ages and ability levels who are placed in non-restrictive environments can learn the skills and behaviors needed to fully participate in society as contributing adults.

This does not mean placing students in the nearest school irrespective of individual needs and abilities, nor does it mean placing students with disabilities into regular classrooms when they need special services. In most cases, a free appropriate public education should be provided to children with disabilities in age-appropriate regular school buildings that offer special education and related services. The Council recognizes that there are situations in which a child's educational needs require placement in an appropriate private school setting or in a specialized public school program. Academic programs must be tailored to meet individual needs while allowing time for disabled and nondisabled peers to be together all or part of each day.

With technical assistance and careful planning, local school districts and parents can establish totally integrated educational programs that are appropriate to a range of needs. School districts in Albuquerque, New Mexico; Madison, Wisconsin; San Francisco, California; and Birmingham, Alabama all have major integration programs that appropriately meet the needs of all children, including those with the most severe handicaps.

A third issue centers on the need to conduct a national assessment of the status of special education today. The National Commission on Excellence in Education and similiar studies have not addressed special education. There is a serious need for a high-level, in-depth study of trends, issues, and problems affecting the nation's system of special education.

1. Congress should amend the Education for All Handicapped Children Act, to encourage States to make available a free appropriate public education to every disabled child from birth through age twenty-one.

To effectively serve children with disabilities, equal educational opportunity under Public Law 94-142, as amended, should be extended to all children beginning at birth. A report by the staffs of Congressman Coats and Miller stated that very early intervention services which benefit children and their parents result in significant tax savings in the long run because of reduced special education expenditures in later years.

The proposed amendments should include the following provisions: a) each State education agency should be the lead and coordinating agency for the services; b) an early childhood specialist should be appointed in each State to ensure that the services are properly planned and implemented; c) Public Law 89-313 funds should follow the child from State institution services to pay for needed community-based services; d) each State education agency and State Medicaid agency should develop interagency agreements that list early intervention services (except for the costs of the educator) as Medicaid reimburseable items; and e) States should develop other appropriate funding mechanisms to meet their individual needs.

2. Congress should direct the Department of Education to promulgate and enforce standards for the application of the least restrictive environment requirement; such standards should clarify that the primary determinant of which educational setting is least restrictive is the educational appropriateness of the program.

The least restrictive environment mandate is a major component of the right to a free appropriate public education for children with disabilities. The principle has not, however, always been appropriately applied by State and local education agencies. In some instance, least restrictive environment has been used as a rationale for educational programs that are more "mainstream" than the educational needs of a particular student dictate. In other instances, the least restrictive environment has not been vigorously applied and children with disabilities continue to be unnecessarily segregated. The Department of Education should provide more direct guidance to education agencies by issuing standards for the application of least restrictive environment principles. Such standards should focus upon educational appropriateness as the critical factor in determining what is the least restrictive program for a particular child. Determining educational appropriateness, in turn, should incorporate a presumption against unnecessary social isolation of children with disabilities.

3. Congress should direct the Office of Special Education Programs to fund a National Technical Assistance Center to help parents and State and local education agencies plan and develop educational options for children with special needs.

To help State and local education agencies and parents appropriately plan for an meet the range of needs of students with disabilities, a national technical assistance center should be funded. This center would provide the staff, materials, and other resources required to help the 57 State and territorial education agencies train parents, teachers, students, and administrators to develop age-appropriate programs for students with disabilities. Materials and information developed by the national technical assistance center would be available for dissemination by the network of special education regional resource centers already in place.

4. Congress should direct the Secretary of Education and the Chairperson of the National Council on the Handicapped to establish a National Commission for the Study of Excellence in Special Education.

Public Law 94-142, as amended, was enacted more than ten years ago. Its enactment has resulted in major changes in the provision of special education services in this country. A special commission should be established to assess what has been achieved and to determine the most cost-effective methods of fully achieving the goals of special education in the future. The Secretary of Education and the Chairperson of the National Council on the Handicapped should each appoint an equal number of members to the commission. The commission should be asked to report its findings and recommendations to Congress within two years of the enactment of this provision.

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TOPIC PAPER I:

PERSONAL ASSISTANCE: ATTENDANT SERVICES, READERS, AND INTERPRETERS

National Council on the Handicapped

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This is one of a series of ten topic papers developed by the National Council on the Handicapped as part of its Special Report to the President and Congress: TOWARD INDEPENDENCE: An Assessment of Federal Laws and Programs Affecting Persons with Disabilities--With Legislative Recommendations. The members of the National Council on the Handicapped wish to expressly acknowledge with appreciation the special contribution made to this paper by Margaret A. Nosek.

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I. INTRODUCTION

Personal assistance is the key to independence for hundreds of thousands of Americans with disabilities. Assistance provided by other persons on a one-to-one basis can enable those with even the most severe disabilities to have opportunities for self-direction and productivity in a setting of their own choice. Many people who need these services, however, are unable to receive them because of a lack of awareness of what personal assistance is, the unavailability of appropriate services in their area, and, most often, a lack of funds to purchase needed services. Often the personal services that prevent placement in institutions are vital to the very maintenance of life for severely disabled people. Because so many environmental factors prevent persons in need from receiving this service, the situation warrants a substantial, coordinated, and effective Federal presence.

Personal assistance services include assistance in carrying out those activities of daily living which, because of functional limitations, individuals are unable to adequately perform for themselves. These limitations may be caused by physical, sensory, mental, or developmental impairment and are usually of long-term duration. Personal assistance can be given in three primary areas: attendants provide assistance for activities of daily living, including basic personal self care tasks such as personal hygiene, dressing, grooming, eating, drinking, using and caring for assistive devices, and mobility; and home care tasks, such as cleaning, laundry, shopping, and meal preparation. Communication assistance, provided person to person and via print, requires the assistance of interpreters and readers. Assistance for cognitive tasks, such as managing finances, planning, and making decisions, requires the assistance of personal advocates. Persons who are blind or have visual impairments require the assistance of technological aids or another person for mobility and for access to printed communication.

This assistance can be acquired in various degrees of formality. On the most informal level, relatives, friends, or other volunteers can be recruited to read aloud personal correspondence, newspapers, magazines, or to assist the individual in getting around the community. Some organizations, such as churches, independent living centers, or civic groups may have organized programs to recruit and refer volunteers to do this type of service. On a more formal level, organizations specifically serving blind persons may refer readers and other types of assistants on a fee-per-hour basis. Requests can also be made of volunteer and fee-for-service organizations to have lengthy documents read on to tape or brailled.

Persons who are deaf or have a hearing impairment require the services of interpreters who are skilled in various forms of sign language. Manual communication may take the form of finger spelling (this is sometimes used exclusively with persons who are both deaf and blind), signed English, American Sign Language (which has a different grammatical structure from English), or a combination of these. Interpreters may also be used to reproduce the spoken word orally for the benefit of deaf persons who are skilled at lip reading. Each of these types of communication requires considerable training and testing for various levels of certification before interpreters can serve deaf persons. Interpreting is a bona fide profession with formal training programs, a code of ethics, professional organizations, and boards to regulate the certification process. Fees for interpreter services vary according to the level of certification. Methods for acquiring the services of an interpreter vary according to local service systems. Some cities have a deaf services agency or independent living center which can refer interpreters and often offer education and counseling services. Deaf people in cities which have no such agencies or centers can sometimes go through the State vocational rehabilitation agency to obtain interpreter services. If even this is not available or if funding for the service is not available, persons with hearing impairments must rely on less formal means to meet their communication needs, such as requesting assistance from relatives, friends, or neighbors.

Persons with mental retardation can often live on their own or in small groups if some degree of periodic supervision is available to help them with the cognitive tasks necessary for independence. Because certain of these tasks involve handling money and making decisions in critical personal areas, persons who provide this type of assistance must meet strict standards of integrity and responsibility. Some local Associations for Retarded Citizens offer programs which link "proteges" (mentally retarded persons) with advocates (responsible adult volunteers).

More formal arrangements are sometimes made through residential institutions and community group homes.

Across these four areas, persons who need personal assistance share many of the same problems, such as inadequate funding and the unavailability in many parts of the country of persons to provide this assistance. For the purpose of brevity and clarity, the detailed discussion below is limited to the topic of attendant services. The recommendations presented in this report, however, refer to all types of personal assistance, including communication and cognitive assistance.

II. THE POPULATION IN NEED OF ATTENDANT SERVICES

With advances in medical treatment and emergency services, an ever greater number of persons are surviving catastrophic illnesses and injuries, often with physical impairments that limit their abilities to perform many of the functions necessary in everyday living. In addition to this post-trauma/post-illness group, a significant number of children are born each year with impairing conditions, including genetically-related neuromuscular disease, mental retardation, and congenital conditions resulting from insult to the unborn child in utero or during birth that limit function and ability to perform activities of daily living. When the number of persons in these groups are added to the number of elderly persons who experience increasing disability resulting from the functional losses associated with various diseases, a substantial number of people with functional impairment require some assistance in performing activities of daily living.

Although data on the actual number of persons requiring attendant assistance on a national basis are not available, it can be safely assumed to be in the millions. Bowe (1984) states that there are 13,102,000 persons between the ages of 16 and 64 with a "work disability." While not all of these persons have disabilities requiring the services of an attendant, it is not unrealistic to assume that a significant percentage does require such services. Existing information from the Health Interview Survey (1979) identifies persons who need "some assistance in four or more activities" as 1% - 1.2% of the population.

However, there is no indication of the extent of these activities; for example, persons who need 20 minutes of assistance per day in minor activities and who probably would not use attendant services are not distinguished from those who need several hours of assistance per day with basic daily living activities and who use attendant services.

In California alone, 100,000 people receive funding for in-home support services, a large part of which are attendant services (Zukas, Cone and Leon, 1984). Sager and DeJong (1977) estimated that for Massachusetts, 34,600 working age adults need help on a regular basis in one or more activities of self care. DeJong (1985) states that the demand for attendant services among working age persons (18-64) can be estimated at 150 persons per one million total population. This estimate assumes that a person needs a minimum of 14 hours of attendant services a week.

The major flaw in most methods for gathering data related to attendant service needs is that they assume need is primarily based on function. Research has shown that functional capacity accounts for only about half of the reason why persons need this service. Family resources, environmental barriers, and availability of technological aids account for the rest.

Quantifying demand is quite different from quantifying need. Demand is a function of availability of funds, attitude toward using the service, availability of persons to provide the service, and awareness of the availability of the service. Utilization data for attendant service programs in various States suggests much lower demand during the first several years of program operation (DeJong, 1985).

Although precise data on the number of persons requiring some form of attendant assistance in order to carry on day-to-day living activities are not currently available, it is obvious from the previous citations and available data that the number is substantial and this represents a significant need in our society. In years past, the only options available to severely disabled persons requiring self-care services were services delivered by family members or services provided in institutional settings such as nursing homes or large State-operated residential facilities. With the changing dynamics of family life, however, and the increasing costs associated with provision of services in institutional settings, these options are becoming less attractive to disabled persons, family members, and purchasers of services.

III. AVAILABLE ATTENDANT SERVICES AND FUNDING RESOURCES

The implementation of attendant service delivery systems has been characterized by considerable variation both in the structure of the systems themselves and in the mechanisms used for funding the services (Nosek, 1985; World Institute, 1985). Since most existing systems rely, at least in part, on funds provided through State-administered agencies, the actual methods for delivery and payment of services have been subject to the mandates, constraints, and idiosyncrasies of the particular legislative and agency requirements of the States in which the systems operate. This diversity has resulted in significant variance from State to State in the scope, quality, and ease of access to services. To date, no comprehensive effort has been put forth to develop a model attendant program that serves all segments of the population in a cost-effective manner while incorporating the crucial concept of consumer control.

Available funding resources are briefly described below.

- Medicaid. This is the primary source of funding for attendant services. However, it is limited by strict maximum income and asset requirements, and services generally can only be delivered under supervision of a medical professional.
- Medicare. Funds available under Medicare are time limited following hospitalization.
- Title XX. In some States, Social Services Block Grant funded programs offer attendant services. Eligibility requirements and regulations for the delivery of services are similar to those under Medicaid.
- Rehabilitation Act of 1973. Within the vocational rehabilitation system, attendant services are authorized

under Title I for persons undergoing evaluation and/or training but may only continue until a very short time after employment is secured. Under Title VII Part A, attendant services are an optional offering; however, no funds have as yet flowed to consumers under this provision.

- Veterans Administration. Under the Aide and Attendant program, disabled Veterans are given a generous monthly allowance to purchase the services they need.
- Education for All Handicapped Children Act, Public Law 94-142. Attendant services are funded as a related service for disabled children receiving a public education, but only while they are at school or participating in a school activity.
- State Programs. Several States have appropriated State funds for attendant services. In some cases, these funds are used for services to persons who work or do not otherwise qualify under Federal programs. In most States, these are only pilot or demonstration programs and service a small number of people.
- Workers' Compensation and Private Insurance. Persons receiving injury settlements under Workers' Compensation or from private insurance carriers often receive designated amounts for attendant services. In order to receive any funds for these services, the individual must often contract for more than is needed in order to meet the requirements of the payee. For example, 24 hour nursing care sometimes must be arranged in order to receive payment when only several hours per day of personal care are needed.

Some of the mechanisms through which these funds are channeled and attendant services are delivered include:

- Home Health Agencies. Most Medicaid and Medicare funds for attendant services are channeled through State administering agencies to Home Health Agencies. After administrative costs are covered, only approximately 50% of these funds remain for direct service to the consumer (World Institute on disability, 1985). Generally, the consumer has little or no control over the choice of persons to provide the service, the type of activities assisted, or the time the service is provided.
- Independent Living Programs. Most centers for independent living offer attendant referral services and training

certified home health providers and channel funds directly to consumers. These services offer the consumer a high degree of control over the hiring and termination of attendants and the manner in and conditions under which services are provided.

- Shared Attendant Programs. Many independent living programs and some private nonprofit organizations operate residential or transitional programs with a pool of attendants available to serve a group of consumers. Services are generally limited to persons residing in designated facilities or apartments.

- Informal Mechanisms. Although nearly impossible to estimate, a large portion of disabled persons who have needed attendant services in the past have arranged for those services through informal mechanisms such as referral by relatives, neighbors, or friends; advertising in the newspaper; use of volunteers from churches, etc. Often, rehabilitation facilities, medical professionals, social service providers, or clergy will refer people they know who may be interested in providing attendant services to disabled persons in need. Many have paid for this assistance from their own resources or through a barter system.

IV. ISSUES

The provision of personal assistance services is a relatively new and often controversial addition to service providing systems. Following is a discussion of several current issues.

A. Definition

There is controversy over whether certain tasks required of attendants are medical or nonmedical. Assistance needed in taking medicine or completing sterile procedures is regarded by medical professionals as a medical service. However, because this type of assistance can be, and often is, rendered by nonmedical persons at the direction of the disabled individual, there is a strong argument for classifying it as a nonmedical service.

The definition of attendant service given earlier implies that, to the maximum extent possible, the assistance provided is controlled by the person receiving the service, and that the service is provided in the most productive and least restrictive environment. However, persons with cognitive deficits may have only a limited ability to make decisions and direct those who assist in meeting their daily needs, and may function more productively in a more structured environment. Attendant service for this population may involve supervision as well as physical assistance, though not necessarily provided by the same person.

B. Eligibility

In establishing a system of attendant services, the most desirable eligibility requirement would be based solely on functional need. Many feel the services should be available as an entitlement to everyone who has a functional limitation which prevents them from adequately performing their daily activities. However, social and economic reality dictates that a national attendant service program will receive very limited appropriations, and will, therefore, need to institute a clear and equitable set of eligibility requirements for receiving the services.

It is the opinion of leaders in this area that this initially strict set of requirements should have functional need as the primary eligibility criterion. The determination of functional need should be based on a combination of factors, including functional abilities, family resources, environmental barriers, and the availability of technological aids. Need is also a function of life style; thus assessment can be highly value laden. There is debate over whether publicly funded attendant services should be more or equally available to working and working age disabled persons than to elderly disabled persons.

The second criterion should be financial need. Determination of financial need should include a very liberal exemption for disability-related expenses.

Given that determination of functional and financial need is complex and value laden, eligibility will be highly influenced by the perspective of the individual who makes the determination. Social workers, occupational therapists, independent living program staff, and the agency that provides the service will all have different influences affecting their decisions. Many think that independent living programs should not provide attendant services themselves, but should advocate for the services to be provided by other community agencies.

C. Delivery of Service

There is widespread agreement that all systems for providing attendant services must allow for maximum control of the service by the consumer. Any requirements which perpetuate the medical model of attendant care in which a third party controls the provision and supervision of the service should be minimized or avoided. This raises the question of whether Medicaid funds should be used for attendant services since they are generally accompanied by requirements based primarily on the medical model. In some States, however, Medicaid-funded attendant programs are less medical in orientation than some Title XX-funded attendant programs.

The issue of consumer control raises the question of whether the consumer employs or directs the attendant. If the individual directs but does not actually pay or control the hiring and termination of the provider, there is doubt that they could truly control the service they receive. Providing funds directly to the individual who then pays the attendants of their choice, however, allows for misuse of the funds. It becomes a question of accountability for the expenditure of public funds versus control over hours, wages, and/or quality of services.

There is debate over what amount of publicly funded attendant services should be allowed per individual. In determining a minimum, there is a threshhold where finding and managing an attendant is more trouble than doing the activity oneself (if that is possible) or having a family member do it. On the other extreme, if a person is given unlimited time for attendant services, abusive situations may arise since there is no incentive to eliminate unnecessary dependence on others.

The questions arise of how much a family can be reasonably expected to do for a disabled member and whether families should be paid for the attendant services they provide. The Liberty Mutual Insurance Company, a major carrier for workers' compensation, found that the spouses of spinal cord injured persons experienced high rates of burnout when they also functioned as attendants. Some years ago, Liberty Mutual found that by paying the spouses $5,000 per year either to hire an attendant or to reimburse themselves, more marriages remained intact and institutionalization was averted. However, paying families for attendant services encourages dependency. This issue is highly influenced by cultural values regarding family responsibility. For example, attendant-type activities are considered the responsibility of the family to a greater extent among some strongly ethnic populations, such as Mexican-Americans, and in rural areas than among urban white persons. Paying an attendant allowance in the form of a voucher to the disabled individual if he or she is of an appropriate age and has the cognitive ability to manage an attendant could solve the problem.

The comment has been made that one could never pay attendants what they are worth, so critical is their service to the productivity and even survival of severely disabled people.

Yet in our society, they are not generally given high status and are usually paid minimum wage. To improve their status and to create a larger pool of quality persons willing to serve as attendants, there should be better marketing of the service and its providers. Attendant services legislation should be constructed so as to ensure that attendants receive adequate wages and benefits.

In order to make the pool of attendants more available to persons who need their services, a registry should be developed in each locality listing individuals with various qualifications who are interested in serving as attendants, similar to registries of interpreters for deaf persons. Attendant services legislation should be worded so as to allow funds for attendant training as one means of making available a pool of attendants with a variety of qualifications. There is general agreement, however, against requiring specific credentials of attendants.

D. Funding

Funding for attendant services come from a variety of sources. Eligibility requirements vary for each type of funding. Some authorities suggest that these services should be coordinated by pooling funds under a single authority and requiring their administration by a single agency. Others feel that a more productive route would be to tap existing Federal and State funds. Federal funds which currently support long-term care institutions could be redirected, as could certain Title XX funds for community services. Within existing programs, definitions and eligibility criteria could be expanded to include more persons who need attendant services. Demonstration line items in

Federal and State agency budgets could be used to support demonstration/utilization/dissemination projects as a means for establishing an expandable foundation for national and State-wide service systems.

A major source of funding for attendant services is the Social Security Act. While the exact amount expended for attendant services under this Act is almost impossible to ascertain, the amount is estimated to be substantial. Anyone who is eligible for Medicaid or Medicare benefits can apply for attendant services through the State administering agency and can receive funding for services if they meet the strict eligibility criteria. The specific titles of the Act under which attendant services could be obtained are as follows:

- Title II: Old Age and Surviving Dependents Insurance. Medicare eligibility could be extended to disabled beneficiaries who engage in substantial gainful activity despite continuing disabilities.
- Title V: Maternal and Child Health/Crippled Children Services. Maternal and Child Health discretionary funds could be used to demonstrate the value of attendant services for adolescents to achieve peer integration and independence. States should be encouraged to provide attendant services in order to reduce hospitalization. The term "disabled" should replace "crippled."
- Title XVI: Supplemental Security Income(SSI). SSI benefits for SSI disabled beneficiaries who require some attendant services could be increased to allow for the expense of attendant services, as is done under the Veterans Administration "essential persons" provision. Similar increases in State supplements could be encouraged. Section 1619 (a) (b), a demonstration project whereby disabled beneficiaries can return to or attempt work and still maintain their Medicaid eligibility, could be made a permanent part of the Act and extended to cover Medicare eligibility as well.
- Title XVIII: Medicare. Coverage of home health services beyond those who are labeled "home bound" could be liberalized and the requirement that a

skilled nurse either provide or supervise these services could be eliminated. Time-limited attendant services to persons leaving hospitals or use of extended care facilities could be extended.

- *Title XIX: Medicaid.* Inclusion of attendant services could be made mandatory under State plans. The income limit could be increased for those labeled "medically needy" to 133% of SSI level, as opposed to the AFDC level (including State SSI supplements). Independent living centers could be included as providers of attendant services. The requirement that services be delivered in the individual's "own home," thus limiting their mobility in the community, could be eliminated.

- *Title XX: Social Services Block Grant.* Attendant services could have authorization and appropriations for additional funding earmarked for three to five years.

There is doubt that attendant programs funded solely by Titles XVIII, XIX, or XX could eliminate their traditional means-tested eligibility and subsequent work disincentives. Funds from Title VII Part A of the Rehabilitation Act could be used to provide attendant services to disabled persons not eligible for services under the Social Security Act. Other sources of block grant funds and/or State funding could be explored for providing attendant services in a cost sharing arrangement in which, for example, individuals would pay no more than 5% of their income for the service's they need. The issue is the separation of eligibility for health and social services from eligibility for income benefits to avert work disincentives.

As a mechanism for disbursing the funds, a type of block grant could be given with a State matching requirement. Funds should be redistributive to equalize services throughout the

States, but wealthier States could enrich their programs, as is currently being done with Supplemental Security Income. Block grants could be part of a long-term care policy for elderly and disabled persons. There is some concern, however, that block grants of Federal money for this purpose could discourage States from establishing programs with pure State money.

E. Cost of Meeting the Demand for Attendant Services

Using DeJong's estimate of the demand for attendant services among working age disabled persons (150 per million population) and statistics from the Current Population Survey (1984) (147 million persons between the ages of 16 and 64), it can be conservatively estimated that 22,050 persons would use attendant services if they were available.

The Metrolina Independent Living Center in Charlotte, North Carolina, conducted a demonstration independent living project using foundation funding. Among all the services delivered in a one year period (July 1, 1984 - June 30, 1985), a total of $64,600 was spent on attendant services for 16 clients at an average of $4040 per year per person; an average of 18.5 hours of service was used per week per person at $4.55 per hour. By applying these usage and payment rates to the national estimate of 22,050 persons needing attendant services, an estimated $96.5 million annually could meet the demand for this service among working age persons.

V. A NATIONAL POLICY FOR ATTENDANT SERVICES

The subject of attendant services was discussed by leaders in the independent living movement and among service providers at three conferences in 1984 and 1985 sponsored by the Independent Living Research Utilization, World Rehabilitation Fund, and National Council on the Handicapped. Each gathering of experts called for a comprehensive national policy for attendant services. With each conference building on the work of the previous one, the following policy guidelines were developed for Federal funding to support a national system of attendant services. The system should:

Serve People with All Types of Disabilities on the Basis of Functional Need. Attendant services have traditionally been designed to meet the needs of physically disabled persons. The concept, however, is applicable to any assistance which compensates for an individual's functional limitation. In this sense, interpreters for deaf persons, readers for blind persons, and supervisors for mentally impaired persons fit within this category.

The need for extensive assistance by persons with severe, multiple impairments is the obvious extreme of this dimension. Persons with less severe limitations may have need of attendant services for small amounts of time or only periodically. However, this relatively minor need may be a crucial link in their independence support system.

Serve People of All Ages. Parents should have the option of having a nonfamily member assist in the care of their disabled child on an occasional, part-time, or full-time basis. Disabled adolescents should have the opportunity of learning to productively manage attendants as part of the transition from school to life in the community. Older persons who have lost certain functional abilities should have the option of utilizing the services of an attendant in order to maintain independence in their own home.

Provide for the Optimum Degree of Self-Direction and Self-Reliance as Appropriate for Individual Consumers. Maximum self-direction involves locating, interviewing, screening, hiring, managing, paying, evaluating, and terminating attendants. Functions such as locating, interviewing, and screening may be performed by an agency or other third party while the individual maintains control of others such as hiring, management, payment, and termination. For persons with limited cognitive function, more third party involvement and supervision may be required; however, control may still be maintained within the abilities of the individual.

Be Accessible to People at All Income and Asset Levels with Cost Sharing as Appropriate. Persons with income or resources near or in excess of the maximum amount for eligibility under certain federally-funded attendant service programs should have the option of purchasing any service offered through publicly funded attendant service providers on a sliding fee or other type of cost sharing basis. An individual should have access to referral and training services, for example, even if they fund the services of the attendant themselves.

Include Assistance with Personal, Cognitive, Communicative, Domestic, and Other Related Services. Activities may include personal or self care (including communication), home care and cognitive tasks, as mentioned in the above definition of attendant services, or assistance with any other tasks which are critical to the maintenance of independence and productivity for persons with any type of disability.

Include 24 Hour, 7 Day/Week Services, Short Term (Respite), and Emergency Assistance as Needed. Attendant services should be regarded as life-sustaining services, and therefore should not have restricted hours for delivery. Service systems should have attendants available on a short term and emergency basis to cover inevitable gaps in the personal support systems of severely disabled individuals.

Be Available Wherever Needed (e.g., Home, Work, School, Recreation, Travel). Services should be available at home, at the workplace, and away from the location of the primary residence. Funding requirements should not limit the geographic mobility of the individual. For example, an individual receiving State funds for their attendant should be able to travel outside of the State and continue to receive the services of that attendant while they travel.

Not Create Disincentives to Employment. Eligibility for receiving attendant service funds should be based on very liberal income and asset maximum requirements, using gross income estimates adjusted for all disability-related expenses. The private sector should explore the possibility of making attendant services available at the work site as an employment incentive for severely disabled persons.

Offer the Consumer a Range of Employer/Employee and Contract Agency Relationships. Consumers should be able to use the Federal funds for which they are eligible to hire attendants on a drop-in or live-in basis or to use any type of employer/employee relationship that is appropriate to their need and preference. They should have the option of contracting services on a long-term regular or periodic basis, or for a short, finite length of time with individuals located, screened, trained and hired by themselves or through a contract agency.

Provide for Outreach and Training of Consumers as Needed. Effective utilization of attendant services requires consumer awareness of the existence and availability of services, and how attendants can help them live more independently and productively. Public information and education activities should be conducted by provider agencies. Many consumers need training in how to effectively use attendant services and how to maintain productive relationships with their attendants.

Provide for Training of Administrators and Staff of Provider Organizations, with an Emphasis on Preparing Organizations Directed and Staffed Primarily by Persons with Disabilities to Provide Attendant Services. Because of the newness of attendant services as a human service profession and service-providing system, and because the independent living philosophy should guide the services being delivered, it is unlikely that traditional program administrators and staff will have the knowledge or experience necessary to operate programs which will uphold these policies. Training is therefore essential to prepare persons with disabilities and consumer-controlled organizations to provide attendant services and to educate attendants and those who use their services. This type of training should be provided for in funding legislation and regulations. Qualified disabled persons who use attendant services should play a significant role in this training nationwide.

Provide for Recruitment and Training of Attendants as Needed. Some disabled persons prefer to hire totally untrained attendants and personally train them to meet their specific needs. Others prefer to know that the persons they interview have been screened by a third party according to certain personal and experience criteria. Those with mental impairments who require assistance in financial management and adherence to medication schedules will need attendants who can pass very strict tests of character, reliability, and experience.

Provide Reasonable Wages and Basic Benefits for Attendants. Attendants should be paid at least minimum wage or a salary similar to that of a provider of comparable services. Opportunities should exist for advancement and increases in salary with increases in qualifications and experience. A mechanism should be developed to assist consumers and provider agencies to offer attendants appropriate benefit packages.

Require Significant Participation of Consumers in Program Policy Determination and Administration. This is a unique and complex area in which consumer control is a foundational element in the philosophy underlying this service. Therefore, it is vital that persons who use attendant services be integrally involved in all levels of policy determination and administration of attendant service programs.

VI. RECOMMENDATIONS

In reviewing the programs services funded by the Federal government, the Council has found that there is an undue reliance on institutional care. The Council believes that personal assistance, as rendered by attendants, readers, interpreters, and advocates, when provided in conjunction with other community-based services, can be an effective and economical means for reducing this Nation's reliance on institutions and enabling most persons with disabilities to live independently in settings of their choice. The goal should be to establish self-directed personal assistant services as one component of a comprehensive array of community-based services that should be available to people with disabilities.

People with severe disabilities have a long-term need for support services. Stable funding and a coordinated system for providing personal services are needed if our society is to develop effective community-based alternatives to institutional care. The Council believes that the following recommendations are essential first steps in reaching this goal.

1. Congress should establish a national policy that defines personal assistance and should require the development of national standards for the delivery of personal services.

A national personal assistance policy should be developed to assure that programs offering personal assistance are required to:

- Serve people with all types of disabilities on the basis of functional need,
- Serve people of all ages,
- Provide for the optimum degree of self-direction and

self-reliance as appropriate for individual consumers,

- Be accessible to people at all income and asset levels with cost sharing as appropriate,
- Include assistance with personal, cognitive, communicative, domestic, and other related services
- Include 24 hour, 7 day a week service, short-term (respite), and emergency assistance as needed,
- Be available where needed (e.g., home, work, school, recreation, travel),
- Not create disincentives to employment,
- Offer the consumer a range of employer/employee and contract agency relationships,
- Provide for outreach and training of consumers as needed,
- Provide for training of administrators and staff of provider organizations with an emphasis on preparing organizations directed and staffed primarily by persons with disabilities to provide personal services,
- Provide for reasonable wages and basic benefits for personal assistants, readers, and interpreters, and
- Require significant participation of consumers in program policy determination and administration.

The development of a coordinated, effective approach to the delivery of personal assistant services requires that a comprehensive definition of these services be incorporated into the Social Security Act, the Rehabilitation Act of 1973, the Education for All Handicapped Children Act (P.L. 94-142), the Developmental Disabilities Act, the Older Americans Act, and Veterans benefits legislation. This definition should be a product of discussions between representatives of major disability groups.

A national policy-making body should set standards for the expenditure of personal assistant service funds to assure that these services are self-directed and responsive to the varied needs of disabled persons and their families.

2. Congress should require the Social Security Administration, in consultation with the National Council on the Handicapped, to implement a series of projects, using SSA demonstration authority and targeting currently available funds, to develop and demonstrate a cost-effective process and mechanisms for the support of community-based personal assistant services for persons with severe disabilities.

The rechanneling of some of the funds that support institutions to support the development of consumer-directed, community-based systems for the delivery of personal assistant services, as rendered by attendants, readers, and interpreters, is a challenging task. It will require careful preparation and step-by-step implementation. The Council believes that a series of demonstration projects would be a productive approach to developing a cost-effective national system of personal assistant services.

A major portion of the resources which support persons with severe disabilities in institutional settings comes from Title XIX of the Social Security Act. While other provisions of this Act enable people with disabilities to receive a variety of social services and income support benefits, strict eligibility requirements regarding income and the involvement of medical professionals in the delivery of services hinder the ability of disabled people to live independently. For a substantial portion of these individuals, lives of considerably more independence and productivity would be possible if funding currently consumed by institutions and services requiring medical supervision could be made available for personal assistant services.

Changes in the language in specific titles of the Social

Security Act could have far-reaching economic implications. Such changes should be preceded by comprehensive studies of the most cost-effective methods for increasing funding for personal assistant services and ensuring that the guidelines for a national personal assistance system are upheld. These studies should significantly involve the input of persons with disabilities in all phases including planning and evaluation.

The recommended projects should be funded under the demonstration authority of the Social Security Administration using currently available funds. While funded by SSA, such projects should address the needs of persons who do not qualify for Social Security benefits as well as those who do. Such projects should:

a. Determine the extent of the national need for personal assistance,

b. Determine the cost of providing services to meet that need,

c. Determine the efficacy of personal assistant services models,

d. Determine the cost-effectiveness of a national personal assistance service plan,

e. Determine the feasibility of implementing a national personal assistance service plan, and

f. Determine the ultimate implications for the Federal budget by evaluating potential savings through reduced institutional costs and enhanced income from increased taxes as personal assistance services enable severely disabled persons to become employed or to live outside of institutions.

These demonstration projects should be carefully designed and evaluated since they would help establish the parameters of a national attendant services program.

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TOPIC PAPER J:

COORDINATION

National Council on the Handicapped

February, 1986

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I. INTRODUCTION

Our Federal system of government is based on laws legislated by Congress and administered by the Federal agencies. To a large extent, the administration of Federal programs mirrors the separations established by the Congressional committee system--each committee (and each agency) is responsible for relatively discrete, functional areas. Coordination problems arise because legislation in one area can have such tremendous effects on other areas. For instance, transportation legislation ultimately affects, among other things, food distribution, interstate commerce, and the ability of disabled people to get from one place to another.

The Federal organization is replicated to a certain extent at the State and local levels. State legislatures and local governing boards also determine policy through legislation, which State governors and local mayors implement. This system creates our "layer cake" system of government. Over the years the layers have become intermingled or "marbelized," as the Federal government has moved into more and more areas that formerly were exclusively the domain of the States. Because of the many interrelationships among the Federal, State and local levels of government, State and local bureaucracies are often organized around the same general functional areas as our national government.

Given this functional organization of our government, it is natural that legislation, and the programs that implement that legislation, are scattered throughout Congress and the Federal government. It is also natural that gaps and duplications occur over time as Congress and the Administration attempt to meet the diverse requests of varied and vocal constituency groups. As a result, it is extremely difficult for any public or private organization to provide the kind of effective coordination that theory might dictate. In reality, effective coordination usually results from a combination of legislative measures, collegial interaction and skillful persuasion. By its actions, Congress has certainly approved the efficacy of the collegial model.

In this report, the Council avoids unrealistic assumptions about the ability of any organization to coordinate services in the abstract sense. The Council does address actions which can lead to a more comprehensive and coherent service delivery system.

This country's disabled citizens are a particularly vulnerable population with a wide range of diverse needs. For this reason, they often need a broader range of services, and encounter greater problems when they encounter disjointed and fragmented services, than do other citizens. Although some inefficiences will always occur in our service delivery system, the Council finds that coordination problems are creating major difficulties for persons with disabilities. Changes are needed that will reduce costs and improve the ability of the system to support the independent living and self-sufficiency goals established in the nation's policy on disability.

II. THE COORDINATION PROBLEM

Coordination is a complex issue that is not subject to simple approaches and solutions. The complexity occurs both at the policy level and in program administration.

A. Policy Development

Policy development is not a clear cut process. It occurs at many levels and in many ways throughout the system. When Congress creates policy by developing legislation, it draws on many sources: assessments of need and program effectiveness, political and fiscal considerations, information about state-of-the art remedies to perceived problems, and the past experiences of the legislators themselves and of the people they consult for information.

Congress often creates programs that are implemented by the Administration. The policy that guides those programs is of course the authorizing legislation, supported by the committee reports that were prepared in the process. Administrative staff use these materials to develop regulations, which become operating program guidelines. Together, the legislation and regulations provide the legal basis for the program. Although proposed legislation normally goes through the committee hearing process which provides an opportunity for wide review and comment by concerned citizens and organizations, the programs that result from this process essentially reflect the functional, separate-track orientation of the development process.

Congress has made a major effort to coordinate its own efforts on behalf of people with disabilities by establishing two subcommittees that specialize in disability issues: the Subcommittee on Select Education in the House of Representatives and the Subcommittee on the Handicapped in the Senate. These committees are supportive of the Council's efforts, and committee staff members make every effort to track and coordinate legislation that affect disabled people. The President and his Cabinet, through their administrative authority, are also actively involved in policy development. They have access to much of the available information about the need for programs and services and the effectiveness of current programs; the way that information is analyzed and presented greatly affects policy development. In addition, program implementation is greatly affected by the amount and quality of attention it receives from top administrators; benign neglect can stifle a program no matter what the official policy. The timing and quality of appointments and the budget control exercised by the Office of Management and Budget are also effective policy tools at the President's disposal.

The White House has demonstrated a strong interest and commitment to the Council's efforts to improve the policies that govern the delivery of services to people with disabilities. For example, in July the White House hosted a luncheon for representatives of the National Council on the Handicapped, the President's Committee on Employment of the Handicapped, the President's Committee on Mental Retardation, and the Architectural and Transportation Barriers Compliance Board. This reportedly was the first official White House briefing ever conducted for Presidential appointees who work on disability issues.

B. Program Administration

Each agency implements its programs by following the guidelines outlined in its regulations. The nature of the regulation-development process, with its stringent adherence to authorizing legislation, means there may be little regard for the impact of one program on another. Each program has its own set of objectives, priorities, and eligibility conditions. Although proposed regulations always go through a comprehensive review process, other program offices may not have the staff resources to adequately review proposed regulations to determine their impact in other areas--we are talking about thousands of pages of regulations.

Coordination efforts are further complicated because programs are managed at different levels in the system. For example, SSDI and Medicare are managed at the national level; SSI, Medicaid and vocational rehabilitation are administered at the State level; and most housing and transportation programs are managed locally.

Since the 1960s, private nonprofit organizations have become increasingly involved in providing services to disabled persons. These services, many of which are funded by Federal grants and private donations, further complicate the service delivery picture since these programs, too, operate according to their own guidelines and priorities. When we talk about the many Federal programs that serve disabled people, it is important to realize that relatively few are targeted specifically at disabled people; the rest serve the general population, which includes disabled people. This is as it should be--in general, disabled people need many of the same or similar services as their able-bodied peers.

Problems result because each agency, following its own regulations and procedures, independently makes decisions about recipients or beneficiaries. For instance, in at least one State some disabled persons nave been denied SSDI benefits, on the grounds that their disabilities were not sufficiently severe, and were also denied Vocational Rehabilitation services because their prognosis for employment was too poor. The problem arises because the Social Security Administration and each State vocational rehabilitation agency uses separate eligibilty criteria. Each program was designed to achieve quite different goals. One provides income support only to individuals who are deemed unable to work because of their disability; the other provides services only to individuals who show promise of being able to work after receiving services. The programs and coordinative mechanisms expected to resolve such problems vary considerably from State to State.

Reports from the White House Conference on Handicapped Individuals in 1977 and from the Forums held by the Council in 1984 and 1985 amply document the extent and severity of these problems. In addition, disabled people repeatedly cite the difficulty of finding information and services: too often they are sent from one place to another in search of services.

III. PAST COORDINATIVE EFFORTS

Over the years both Congress and the Administration have responded to the coordination issue. For instance, in 1978 Arabella Martinez, then Assistant Secretary for Human Development, proposed an administrative reorganization within the Department of Health, Education and Welfare that pulled together the Rehabilita- tion Services Administration, the Developmental Disabilities Office, the President's Committee on Mental Retardation, the Office for Handicapped Individuals, and the Architectural and Transporta- tion Barriers Compliance Board. The new Administration for Handicapped Individuals died aborning when the Rehabilitation Services Administration and Special Education were moved to the Department of Education.

The original mission of the Office of Handicapped Individuals (OHI), which was created by the Rehabilitation Act of 1973, was to coordinate programs for disabled people. It failed because it was unable to rapidly accummulate knowledge about Federal programs, and lacked the staff resources needed to pinpoint coordination needs and to effectively advocate for disabled people before other agencies. The Information Clearinghouse on the Handicapped, which was lodged in OHI, was moved after the demise of OHI to the Office of Special Education and Rehabilitative Services. The Clearing- house is now also defunct; some of its functions are being conducted under contract.

An Administration on Disabilities has been proposed repeatedly over the years as a solution to the coordination problems in the disability field. Although past attempts in the disability field have failed, an approach which may work is in place: the Older Americans Act created an Administration on Aging that provides a focal point for issues of concern to elderly persons. The implementation of the Act has resulted in increased interest, programs and funding in the aging field. The Administration on Aging has a unique network of 57 State and some 700 area agencies that provide statewide planning and social services at the local level, including multi-purpose senior centers with information and referral services. Some of these area agencies are very effective conduits for local public and private sector networking and community action activities. In fact, the strength of the Older American's Act is grounded in the services and activities of the area agencies on aging.

Although it was not primarily a coordinative effort, the White House Conference on Handicapped Individuals was a major, national policy development effort that obtained information on policy issues from disabled consumers all over the country. The Conference gave rise to governor's and mayor's committees that guided and coordinated local efforts; some of these committees survive today.

As a direct result of the White House Conference recommendations, an advisory position was created in the White House. The influence and impact of the position, which is now held by a Senior Staff Member in the Office of Policy Development in the Executive Office of the President, depends on the political expertise and ability of the incumbent. The Conference also gave rise to the National Council on the Handicapped, which is discussed in the following section.

IV. CURRENT COORDINATIVE EFFORTS

A number of interagency entities address specific aspects of services to disabled people. Brief descriptions of several of these entities follow.

- The Architectural and Transportation Barriers Compliance Board is an independent board composed of heads of a number of Federal agencies and departments. Its activities are regulatory in nature and are limited to architectural and transportation accessibility compliance issues.
- A Federal Agency Council advises the Census Bureau on census topics and issues.
- The Interagency Committee on Handicapped Employees is mandated by Section 501 of the Rehabilitation Act of 1973. This committee addresses employment issues within the Federal Government.
- A Disability Advisory Committee has been proposed to provide advice on disability issues within the Social Security Administration.
- The Interagency Committee on Handicapped Research is chaired by the Director of NIHR. Its membership includes agency heads designated by the President. The Committee has a mandate to identify, assess, and seek to coordinate all Federal program activities related to rehabilitation research.
- The President's Committee on Employment of the Handicapped emphasizes public outreach to increase employment of disabled people.
- The President's Committee on Mental Retardation was created during the 1960's in response to the Kennedy Administration's recognition of the need to develop services for mentally retarded individuals.
- The Administration on Developmental Disabilities was established by the Developmental Disabilities Assistance and Bill of Rights Act of 1963. The Administration provides a national planning focus for programs that serve individuals with developmental disabilities.

In addition, Congress mandated an Interagency Coordinating Council in the Rehabilitation Act of 1973 (amended February 22, 1984, PL 98-221), under Section 507. It is composed of the Secretary of Education, the Secretary of Health and Human Services, the Secretary of Labor, the Attorney General, the Chairperson of the Office of Personnel Management, the Chairperson of the Equal Employment Opportunity Commission, and the Chairperson of the Architectural and

Transportation Barriers Compliance Board. Executive Order 12250 names the Attorney General as chairperson, a function which he has delegated to the Assistant Attorney General for Civil Rights. The Council is to develop and implement:

> ...agreements, policies, and practices designed to maximize effort, promote efficiency, and eliminate conflict, competition, duplication, and inconsistencies among the operations, functions and jurisdictions of the various departments, agencies, and branches of the Federal Government responsible for the implementation and enforcement of the provisions of this Title and the regulations prescribed thereunder.

The Council's report on its activities is to be filed annually on July 1. Thus far the Council has met six to eight times per year to address issues related to Title V. The Council does not now include the National Council on the Handicapped.

V. NATIONAL COUNCIL ON THE HANDICAPPED

Congress created an independent National Council on the Handicapped (NCH) to provide advice on disability policy to the Administration and Congress. In addition to its responsibilities to advise the Commissioner of the Rehabilitation Services Administration on policies and programs, and to provide policy direction to the National Institute of Handicapped Research, Congress required NCH to:

> (4) Review and evaluate on a continuing basis all policies, programs, and activities concerning handicapped individuals and persons with developmental disabilities conducted or assisted by Federal departments and agencies, including programs established or assisted under this Act or under the Developmental Disabilities Assistance and Bill of Rights Act, in order to assess the effectiveness of such policies, programs and activities in meeting the needs of handicapped individuals (Sec. 401 (a), P.L. 98-221).

Congress reinforced the breadth of this mandate by requesting that the Council:

> (7) Provide to the Congress on a continuing basis advice, recommendations, and any additional information which the Council or the Congress deems appropriate (Sec. 401 (a), P.L. 98-221).

Coordination issues are certainly one of the Council's major responsibilities under this broad mandate. For instance, the Council is recommending in its February, 1986 Special Report to the President and Congress that a Comprehensive Equal Opportunity Law be enacted. Such legislation represents a major step toward providing equal opportunity for disabled people. Enactment of this legislation would establish an important precedent and would directly affect the provision of employment, transportation, and housing services to disabled people.

The National Council on the Handicapped has a mandate which places it in a particularly advantageous position to work on a collegial basis with other Federal agencies. It is in a position to use its persuasive powers to identify gaps and overlaps within the service delivery system, and to advise Congress and the Commissioner of the Rehabilitation Services Administration on specific measures by which services to disabled people can be improved. As part of its duties, the Council establishes general policies for and reviews the operations of the National Institute of Handicapped Research. In line with that responsibility, the Council plans to use its ex-officio membership on the Interagency Committee on Handicapped Research to support Federal Government agency research on coordinative issues. The Committee's tentative plan to convene consumers and Federal, State and local agency representatives to participate in state-of-the art seminars and conferences on coordinative issues is strongly supported by the Council.

The Council also intends to increase its interaction with private sector organizations concerned with disability. We will continue to emphasize and strengthen our consultations with other public agencies and committees working on disability topics. In addition, the Council will redouble its efforts to inform Congressional staff members about the status of and need for improvements in Federal programs serving disabled people. The Council will monitor and report annually to Congress on this nation's progress on the agenda laid out in the Council's Disability Policy Statement and on the recommendations set forth in its Special 1986 Report to the President and Congress.

In conclusion, the Council intends to use its unique position as an advisor to both Congress and the Administration to increase the sharing of information and to help build better and stronger linkages among relevant policy makers and the programs that serve disabled people.

VI. RECOMMENDATIONS

"Coordinated services" describes the ideal results of a wide range of interactions among persons active in policy and program development. Although these interactions take place every day, their purpose, frequency and quality varies greatly from community to community, from State to State, and from program to program. In the Forums conducted in 1984 and 1985 as part of the Council's preparation for its Special Report to the President and Congress, disabled people around the country declared that many programs do not mesh well with other available services, and that too often the service delivery system exhibits gaps, inconsistencies and inequities. However, there is no single or simple solution to the need for better coordinated services. Therefore, the Council believes that mechanisms should be in place throughout the service delivery system that consistently and purposefully attempt to improve the linkages among the policy makers and programs that serve disabled people.

After a careful study and review of the current service delivery structure, we have determined that the Council itself has a unique mandate from the Congress to facilitate the implementation of a coordinated disability policy at the national level. The Council's disability policy statement, which has been approved by the President, and the assessment and recommendations in the Council's Special Report to the President and Congress, represent major steps in this direction.

The Council appreciates the importance of frequent and purposeful interaction at the national level with all parties involved in policy decisions that affect services to people with disabilities. To that end, the Council pledges to maintain its information base with consumer organizations around the country while strengthening our interaction on coordination issues with State, local and national policy makers, private organizations, the Congress, and the

Administration. This process will continually identify coordinative issues which can best be resolved through specific legislative or administrative action. In addition to these national level activities, State and local planning by recipients of Federal funding should take place in every community. To reinforce the importance of such coordinated planning, the Council makes the following legislative recommendation:

1. Congress Should Require State and Local Agencies that Receive Federal Funds for Services for People with Disabilities to Participate in the Development of Coordinated Service Delivery Plans.

A State planning requirement is in place for citizens with developmental disabilities. The Council recommends that the planning process should address the needs of all citizens with disabilities and that it should be extended to the local level as well as the State level. The planning process should seek the involvement and participation of existing planning mechanisms in each State and community. For this reason, lead agency responsibility and a detailed schedule for the creation of such plans should be assigned by the appropriate governor or mayor.

At a minimum, State and local agencies that receive or administer Federal funds for the following benefits and services should participate in the planning process: Veterans benefits and services; Social Security disability income, health services, long term care and medical insurance programs; education; rehabilitation and independent living services; Title XX; Worker's Compensation; employment and training (Job Training and Partnership Act); housing and transportation; developmental disabilities planning and services. In addition, the process should, by requirement and design, substantively involve people with disabilities in the planning process. The planning process should specifically address methods of improving service delivery. Particular attention should be paid to the needs of individuals with disabilities who do not fit neatly into established service categories. For instance, careful planning should prevent persons with disabilities who are declared ineligible for SSDI from being denied vocational rehabilitation services. It should assure that appropriate services are delivered to people with multiple handicaps, such as the estimated 15-20% of mentally retarded individuals who also have emotional problems. In States and local communities, the planning process should lead to improved communications, more integrated services and better informed policy discussions. No additional Federal costs are associated with this recommendation; if implemented in good faith at the State and local levels, the planning process should lead to improved services at equal or reduced costs.